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Long-term Subjective Quality of Life and Adjustment following Traumatic Brain Injury

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requirements of
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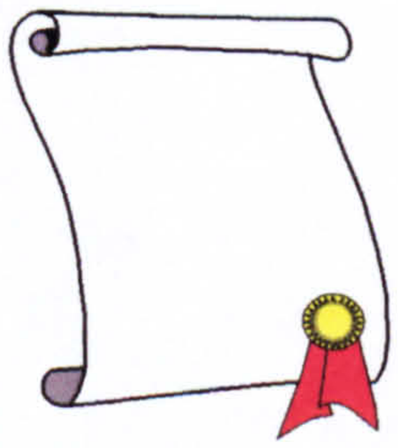

October 2001

"How to gain, how to keep, how to recover happiness is in fact for most men at all times the secret motive for all they do"

-William James-
1903

"Not as I wish, but as I am"

-Claudia Osborn-
1998

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Specific thanks are due to my two supervisors, Dr Roger Lamb and Dr Neil Brooks. They have both put in much time and effort and I have valued their advice and their thorough and useful comments on earlier versions of this thesis.

I am particularly grateful to the late Dr Freda Newcombe, who died in April 2001. It was significant that all brain injured people and their families who knew her held her in such high esteem. Her human approach and her dedication to her clients have inspired much of my own thinking in relation to outcome research and clinical practice. Since I first met her in 1993, she has been very kind and more than patient with me. I am therefore much saddened by the fact that after all those years, she is not here to see the ending of this project.

A great many brain injured people and their families have given up time to be interviewed and to complete questionnaires for this study. All but one of the brain injured people approached, agreed to cooperate with the study, possibly a sign of their need to be heard, their drive to help expand knowledge about the long-term consequences of a traumatic brain injury, and the failure of long-term care in meeting the needs of people with head injuries. Many local HEADWAY houses also cooperated in the recruitment of brain injured people for this project, and their help has been much appreciated.

Finally, I would like to thank all those who have helped me finish this project, including (amongst others) Roger Fitzsimmons, Edward de Haan, Bobbi Haydon, Jian-Bin Shih, Tina Cartwright, Rachel Reeves, Tilly Jacobs-Wensing, and other members of my family for keeping their faith in me. Emily, my wife, has had to endure much while I finished this project, and I am hereby offering her my apologies, and a promise that I will never again tell her I cannot do something because of my PhD.

Subjective Quality of Life and Adjustment Following Traumatic Brain Injury

It is clear from research that a traumatic brain injury has persistent consequences that force a person to change life goals and fundamental beliefs about the self. Two relatively under-researched areas in the field of traumatic brain injury are long-term outcome, and self-perceived outcome. This research combines the two in order to investigate long-term subjective quality of survival.

The two main research questions formulated were:

1. What is the subjective quality of life of a sample of brain injured people compared to that of a matched, non-clinical control group.
2. Can subjective quality of life be predicted using injury-related variables and adjustment-related variables?

Overall, it would seem that brain injured people had managed to adapt very well to the long-term consequences of their traumatic brain injury. They experienced the same global subjective quality of life as a matched control group, and scored similarly in terms of 14 out of 16 domains of satisfaction. However, brain injured people did not adapt in all life domains, particularly not in terms of satisfaction with their mental abilities, their sexual life, and not having a partner.

It would also seem that a number of adaptive tasks are highly related to this outcome, including the way the patient perceives his own problems, whether he has incorporated his limitations into his new perception of himself, and whether he no longer compares his present situation to his pre-injury past. At the same time, the patient's objective health status in terms of his post traumatic amnesia and cognitive deficits was not related to subjective quality of life at all.

In 35.5% of all interviewed cases, either the brain injured person or the significant other responded with 'yes' to questions whether the brain injured person had ever attempted to commit suicide.

Brain injured people reported positive effects in terms of changes in self-perception, understanding social relations, and life orientation.

The results in this study are contrasted with those found in other fields, discussed within a subjective and an appraisal approach, and the clinical implications that arise from this thesis are spelled out.

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CHAPTER ONE TRAUMATIC BRAIN INJURY[1]

1.1. INTRODUCTION TO THE THESIS

Immediately following a traumatic brain injury, the main concern of clinicians and carers is the survival of the person involved in the accident. Improved brain scanning and neurosurgical techniques have resulted in a dramatic increase of the survival rate in the last 30 years (Ponsford et al., 1995). Many more people will therefore survive injuries to the head and enter the next phase, in which there is typically a gradual improvement of functions. Despite some indications that cognitive and behavioural improvement occurs over time (e.g. Thomsen, 1990) it is clear that in most cases recovery of functions is incomplete and that most progress takes place in the first few months following the accident. The amount of change a person with a traumatic brain injury subsequently has to face, depends firstly upon the ensuing physical, cognitive, behavioural and emotional deficits, and secondly upon the client's perception of these consequences. Some people are able to resume their life largely as it was before the accident. Others are confronted with changes that affect many areas of their life from work to leisure, from mobility to social relationships. As a result of this sudden pervasive change in their lives, many people with a traumatic brain injury will have to abandon ideas about themselves, about others and about the future, which they had before their accident. Much research has been done on the actual consequences of traumatic brain injury; Much less attention has been focused on how brain injured people adjust to the ensuing limitations, how they may change their perception of their own life and what the role of specific sequelae are in terms of the client's adjustment.

This thesis is concerned with two basic questions which have not received much attention in the literature:

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[1] The term 'Traumatic Brain Injury' always refers to *severe* traumatic brain injury in this thesis, unless stated

1. What is the long-term subjective quality of life of a group of severely brain injured people?
2. How can subjective quality of life be predicted? Particular attention will be focused on the question whether objective, injury-related variables and adjustment-related variables are good predictors of subjective quality of life.

An attempt to start answering these two ambitious questions will be made in this thesis.

Chapter one is an introduction to the effects of traumatic brain injury, focusing in particular on the long-term consequences and on the gaps in the literature.

Chapter two introduces the concept of a traumatic brain injury as a critical life event. This conceptualisation (of a traumatic brain injury as a critical life event) is useful because it means that a traumatic brain injury can then be compared to other illnesses or conditions which have also been classified as critical life events.

Chapter three focuses more on how people generally adjust to critical life events and introduces a general model of how people with a traumatic brain injury adjust to the consequences of their traumatic brain injury.

Chapter four focuses on the measurement of outcome, and introduces the concept 'subjective quality of life'. It also discusses whether subjective quality of life has been found to be related to objective, injury-related variables in other clinical fields, such as the field of spinal cord injury.

Chapter five then presents the specific research questions and hypotheses that follow from the theoretical introduction in chapters 1 to 4, and also includes the research methodology used in the study.

Chapter six describes the development of the Satisfaction with Life Domains Scale for Traumatic Brain Injury, which is used in analyses in the rest of this study. It also includes the development of the Life Priority Scale and the Future Expectations Scale.

Chapter seven investigates the subjective quality of life of a group of severely brain injured young men compared to that of a matched control group.

Chapter eight investigates the relationship between subjective quality of life and injury-related variables, such as post-traumatic amnesia, and self- and carer-perceived neurobehavioural problems.

Chapter nine looks more closely at the relationship between subjective quality of life and adjustment-related variables, such as level of awareness, level of acceptance of

limitations, and past-future orientation. It also introduces qualitative data to investigate the relationship between level of adjustment and subjective quality of life in more detail.

Chapter ten considers other variables which may influence subjective quality of life (such as time post-injury). It also looks more closely at variables which could be considered markers of good or bad adjustment, such as whether the client has attempted to commit suicide and whether the client can see positive effects of having gone through the experience of having suffered a severe traumatic brain injury.

Chapter eleven contains the summary, the discussion, and the theoretical and clinical implications of the results.

1.2. TRAUMATIC BRAIN INJURY

A traumatic brain injury can be defined as "*a definite history of a blow to the head, a laceration of the scalp or head, or altered consciousness no matter how brief*" (Teasdale, 1995). The definition of the US National Traumatic brain injury Foundation adds the fact that it results in impaired cognitive abilities or physical functioning (NHIF, 1989). A distinction is often made between primary brain damage - occurring at the moment of impact - and secondary damage - as a result of later complications (Teasdale, 1995). Primary damage can have three possible causes (Kolb and Whishaw, 1990).

First, the *coup* effect causes damage at the site of the impact.

The intracranial impetus generated as a result of the blow to the head forces the brain against the skull, 180 degrees opposite the site of impact. This is called the *contre-coup* effect. Both coup and contre-coup result in focal brain damage, often restricted to the frontal and temporal areas of the brain.

Thirdly, the forces exerted on the brain cause it to accelerate, decelerate and rotate very fast. This may cause nerve fibres to shear, thus producing microscopic lesions in the brain (Oppenheimer, 1968; Ommaya and Gennarelli, 1974). Shearing effects tend to be concentrated in the frontal and temporal lobes, and the interfaces between grey and white matter around the basal ganglia, periventricular zones, corpus callosum, and brain stem fibre tracts (Levin and Kraus, 1994).

Secondary brain damage can be the result of intracranial processes, for example brain swelling, raised intracranial pressure, haematomas or infection; or it can also result from damage to other parts of the body, for example hypoxia, hypotension or fever (Teasdale, 1995). The combined pathology brought about by primary and secondary damage leads to focal and distributed injury in the brain. Focal brain damage results in selective neuropsychological deficits and damage distributed throughout the brain produces more generalised deficits. It is often thought that the generalised deficits are responsible for the quality of the recovery (Ponsford, 1995; Lishman, 1998).

1.3. MEASURING THE SEVERITY OF TRAUMATIC BRAIN INJURY

There are a number of ways of to measure the severity of a particular traumatic brain injury. The most commonly used are:

1. The Glasgow Coma Scale Score on admission; Teasdale and Jennett (1974) developed a scale to assess the depth and duration of coma. Three variables are measured, independently from each other: motor response, verbal response, and eye opening. This scale is now widely used clinically and has been shown to be related to damage in the central areas of the brain, neuropsychological impairments (Wilson, Teasdale, Hadley, Wiedmann, and Lang, 1993), and post-injury cognitive outcome (Brooks, 1990). It is standard clinical practice in Accident and Emergency to measure Glasgow Coma Score following an admission for a suspected traumatic brain injury.
2. The length of coma (LOC); The duration of coma has been defined as the interval between injury and the point at which the patient was consistently out of coma, namely when his eyes are open, he speaks comprehensibly, or if he obeys commands (Wilson et al., 1993). Most researchers, however, do not describe when they consider a person to be out of coma. A further drawback of using length of coma is that it is not always clear when a person has become conscious, unless the definition of conscious versus unconscious states is made explicit and clear. However, waking up from a coma is a gradual process with a number of different stages (Wilson, Shiel, Watson, Horn, and McLellan, 1994). Furthermore,

consciousness may be suppressed by medication, so that it is not clear when a person has woken up from his coma.

3. The length of the period of retrograde amnesia (RA) has been taken as a measure of the severity of traumatic brain injury (Lezak, 1995). This is defined as loss of memory for a period of time preceding the accident. Not much work has been done on the relationship between RA and post-injury outcome.

4. The length of the period of Post Traumatic Amnesia; Russell (1932) originally used the capacity to store current events as a measure of the end of the period of post traumatic amnesia. The full duration of post traumatic amnesia includes the period of coma plus the period following a traumatic brain injury in which the patient has not regained continuous memory. It has been described as a reliable index of severity (Smith, 1961; Wilson et al., 1993), correlating with both central and hemispheric brain damage, neuropsychological impairments, and occupational status. Table 1.1. lists the classification of severity used by most authors. Van Zomeren and Van De Burg (1985) suggested that 13 days is a better cut-off point between severe and very severe traumatic brain injury. This finding was confirmed by Brooks et al. (1987a). Post traumatic amnesia can be measured prospectively - when the patient is in post traumatic amnesia - or retrospectively by interviewing the patient and/or somebody who has been with him during his stay in the hospital. Unlike the Glasgow Coma Score, measuring post traumatic amnesia prospectively is not standard clinical practice and it therefore has to be estimated retrospectively in most cases.

Table 1.1 Classification of severity, based on the duration of post traumatic amnesia (Russell, 1971)

PTA Duration	**Classification**
< 5 minutes	Very mild
5-60 minutes	Mild
1-24 hours	Moderate
1-7 days	Severe
1-4 weeks	Very severe
More than 4 weeks	Extremely severe

1.4. EPIDEMIOLOGY

The main causes of traumatic brain injury are falls (either a person falls on the floor or an object falls on the head), assaults and road traffic accidents. Road traffic accidents are the most frequent causes of more severe head injuries (Teasdale, 1995). This may be because the head is already moving at the time of impact, thus increasing the velocity of impact and the forces that are generated (Kolb and Whishaw, 1990).

Almost one million people go to a hospital every year in the United Kingdom to be treated for a traumatic brain injury (Jennett and MacMillan, 1981). In the USA, Australia, France and Spain, the incidence of death from traumatic brain injury is reported as 20-30 per 100000, whereas in the UK the rate is approximately two thirds lower at 7 per 100000 (Jennett, 1996). The vast majority present with a mild traumatic brain injury and and do not need any further care (Jennett, 1998). Head injuries are less common in the United Kingdom than in many other countries (Jennett, 1998). Every year, 10-15 people per 100.000 suffer a severe traumatic brain injury, 15-20 people suffer a moderate traumatic brain injury, and 250-300 people sustain a mild traumatic brain injury. There are a number of predicting variables for sustaining a traumatic brain injury. The typical brain injured person comes from the lower socio-economic classes, has little education, and may not have had employment prior to the injury (Alberts and Binder, 1991; Ponsford, 1995). There is also a high proportion of pre-morbid substance abuse, particularly alcohol, in this sample (e.g. Bond, 1984). All this leads to the situation in which most brain injured people sustained their injury when they were young and men greatly outnumber women.

1.5. OUTCOME FOLLOWING TRAUMATIC BRAIN INJURY

Conkey (1938) reported some very early references to the effects of traumatic brain injury on behaviour. Hippocrates described grave symptoms and contralateral convulsions following trauma to the head. In the first century A.D., Celsus suggested that cerebral haemorrhages could occur without injury to the skull. Lanfrancus first used the term 'commotio cerebri' in the 13th century. Various people observed in the 16th and 17th

century that a blow to the head could result in brain damage, even though the skull was not fractured nor were there any external injuries.

With the advent of phrenology in the late 18th and early 19th century, research into the brain and the effects of brain damage became more widespread and resulted in an increase in knowledge. The consequences of traumatic brain injury were described in great detail. In 1839, the French surgeon Dupuytren emphasised the persistence of the consequences of traumatic brain injury and in 1889 the German physician Oppenheim published a monograph on traumatic neuroses. The focus was mainly on the somatic symptoms until Meyer described the mental sequelae as follows: *"...fatigue, slowness of thought, inability to keep impressions, irritability, and a great number of unpleasant sensations*". In 1916, Horn distinguished between the effects as a result of the blow on the head and the effects as a result of various psychological factors during the recovery. In 1934, Grant pointed out the importance of the psychological approach to the sequelae of traumatic brain injury when he stated: "*Mortality statistics are more important to the surgeon, while morbidity statistics are much less emphasised but are of infinitely greater importance to the patient and to society at large. A patient may recover, but be so handicapped by post-traumatic sequelae that his economic value to himself and his dependents is greatly reduced*". Conkey (1938) was one of the first to use robust psychometric procedures when she compared a group of brain injured people with two control groups (one healthy and one with various conditions) on a battery of tests and was thus able to document the cognitive consequences of traumatic brain injury. She also demonstrated that patients recovered to a certain extent during their stay in the hospital. She stressed the fact that "*all performance fields were affected to a greater or lesser extent...*" (p.53) and that brain injured patients seem to have lost the ability to perceive abstract relationships and have a very concrete attitude. Goldstein (1934, 1995) made a similar clinical observation.

There has been much debate over whether the changes associated with traumatic brain injury are the result of 'post-traumatic compensation neurosis' or the result of damage to the brain. This was due to the fact that in autopsies, no or very few gross lesions were found in the brain which would account for changes in behaviour. However, Gordon (1933) stressed the impact that small, diffuse haemorrhages in the brain could have. Many people were still not convinced. For example, Miller and Stern (1966) observed

that, especially in the case of minor traumatic brain injury, "*...the subjective complaints in such cases nearly always resolve without treatment after settlement of the financial issues involved*" (p.225), although -to be fair- they do very generously concede that in many cases of severe traumatic brain injury "*the genuineness of such disablement is unquestionable*" (p. 225). It would seem that certain symptoms are the direct result of the brain damage, whereas others are in response to the symptoms. Evidence for this comes from the fact that certain changes are consistently related to the severity of the accident (such as memory, slowness), whereas others are not (for example, irritability) (Van Zomeren et. al., 1983). Furthermore, studies have shown the minuscule, diffuse white matter damage to the brain (e.g. Adams, 1975). There is also little support for the view that many patients become symptom-free following settlement (Mendelson, 1982).

The last two decades have seen an increased interest in the sequelae of traumatic brain injury. Three fields are responsible for this (Diller, 1994): the assessment of recovery following traumatic brain injury, changes in service delivery practices, and functional assessment in rehabilitation. The main focus of interest has shifted from neurological symptoms to aspects of outcome which occur later on and which are more salient to the individual's personal and home situation. Psychiatric sequelae (Lishman, 1973; Rosenthal and Bond, 1990), cognitive impairments (e.g. Levin et al., 1979), personality changes (Brooks and McKinlay, 1983; Brooks et al., 1987a), social recovery (Oddy and Humphrey, 1980), employment (Humphrey and Oddy, 1980; Brooks et al., 1987b) and outcome for the family of the brain injured subject (Oddy, Humphrey, and Uttley, 1978; Lezak, 1978; Brooks, 1991) have been investigated. It has been demonstrated that traumatic brain injury has an adverse effect on family functioning and family satisfaction (Brooks, 1991; Kreutzer et al., 1994). Many reviews have appeared in the literature, for example of the cognitive impairments following traumatic brain injury (Newcombe, 1982; Brooks, 1990; Levin, 1992; Ponsford, 1995) and the emotional and psycho-social sequelae (Prigatano, 1992; Kreutzer, Devaney, Myers, and Harris Marwitz, 1991). What has not been reviewed is the literature on the long-term consequences of traumatic brain injury (i.e. more than one year post-injury).

1.6. LONG-TERM NEURO-BEHAVIOURAL AND PSYCHOSOCIAL CONSEQUENCES OF TRAUMATIC BRAIN INJURY

A search using MEDLINE and PSYCHINFO was done with the following key words: '(brain injury or traumatic brain injury) and (outcome or quality of life) and long term' The articles were then selected using the following criteria:

1. The brain injured sample has suffered a *moderate to severe* traumatic brain injury[1];
2. The time post-injury of each participant should be over 1 year post-injury. Van hoofien et al. (2001) stated that early studies (usually before the 1980s) referred to the acute and post-acute stages of recovery and these were therefore not included in this review.
3. The quality of the research design should be of high enough standard (e.g. no retrospective rating of symptom levels) and should not deviate too much from the standards of research design described below, which were based on those developed by Sherer, Novack, Sander, et al. (2002) and Heaton, Barth, Crosson, Larrabee, and Reynolds (2002).
4. The study should describe <u>specific</u> long-term cognitive and psycho-social sequelae. This rules out some of the early work by for example the Glasgow group of Bond and Jennett (e.g. Jennett, 1984; Jennett and Bond, 1975) which described more general and cruder aspects of outcome for head-injury survivors.
5. English language articles

Sherer et al. (2002) reviewed studies investigating the relationship between neuropsychological assessment and employment outcome after traumatic brain injury. They adapted a number of guidelines developed by Heaton et al. (2002) to evaluate the methodological adequacy of the studies reviewed. These guidelines were largely adopted for the critical evaluation of studies in the present review. The best type of study is one which has high generalisability and reliability. It should be a prospective study of a consecutive series of patients; sampling should be adequate to ensure

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[1] It was decided to include studies in which the <u>*average*</u> PTA was moderate or severe.. This means that a number of studies were reviewed which did include mild head injuries but in which the average head injury severity was moderate to severe

generalisability to the population of interest; participants lost to follow-up are described; and reasons for failure to return to follow-up are mentioned; analyses permit specific conclusions about predictive power (Sherer et al., 2002). Sherer et al. (2002) gave guidelines with regard to the adequacy of methodology. These were adapted for the present study and are described below.

The participants:

1. The method of recruitment should be well described.
2. The participants should be representative of a larger TBI population (preferably a consecutive series of admissions).
3. The sample should be well described in terms of:
    - age;
    - sex;
    - education;
    - cause of injury;
    - severity of injury;
    - time from injury to assessment of outcome or predictors;
4. Adequate sample size.

Data collection:

1. Reliable and valid measures are used.
2. Clear description of method of data collection.
3. Single-sourced or multi-sourced data collection.

The methodology:

1. Prospective rather than retrospective methodology.
2. Preferably a consecutive series of patients and preferably multi-centre.
3. Longitudinal or cross-sectional study.
4. Methodology clearly explained.

The analyses:

1. Adjustment is made for multiple comparisons.

2. Analyses are done comparing patients lost to follow-up to those who were available for follow-up.

3. Power calculations were carried out.

Table 1.2. shows summaries of 19 studies investigating the cognitive and/or psychosocial outcome of brain injured people who are more then 1 year post-injury.

Table 1.2. Summaries of 12 long-term outcome studies between 1983-2002

Author and year	Population	Methodology	Main Findings	Critical evaluation of study
1. Van Zomeren and ven den Burg, 1983	▪ N = 57; 51 men; 7 women ▪ Mean PTA 30 days ▪ Mean age 26.6 years ▪ Time post-injury: 2 years ▪ 'Pure' blunt TBIs	▪ Questionnaire re self-perceived neurobehavioural problems	▪ 84% reported some residual complaint, with memory (54%) top of the list, then irritability (39%), slowness (33%) and poor concentration (33%). ▪ Forgetfulness, slowness, poor concentration, inability to do two things at once all significantly related to PTA ▪ 'Behavioural' consequences not related to PTA	▪ TBI group ranging from mild to severe, skewed towards severe ▪ Questionnaire used not described adequately ▪ Recruitment process inadequately described STRENGTHS ▪ One of the earliest studies of self-perceived problems; Much quoted thereafter ▪ Relationship between PTA and symptoms described
2. Thomsen, 1984	▪ Severely brain injured people, Just under half with aphasic problems as well ▪ PTA > 1 month ▪ N = 50 after 2-5 years ▪ N = 40 after 10-15 years ▪ Mean age mid twenties	▪ Cross-sectional design ▪ Questionnaire filled in by a close relative on two occasions: 2-5 years and 10-15 years after the accident ▪ Neuropsychological testing	▪ Memory problems reported by carer did not diminish significantly ▪ Two thirds had permanent changes in personality, emotion and social contact ▪ Hardly any had contacts outside the close family ▪ Social isolation remained the patients' severest burden ▪ Changes in personality and behaviour continued to be a serious burden and were permanent for two thirds	▪ No description of 20% of patients lost at follow-up ▪ No description of the measures used (including measurement of PTA); Rather, the author simply stated the outcome without referring to the measures ▪ Method of recruitment not described and generalisability to general TBI population therefore not clear STRENGTHS ▪ First long term outcome study; Much quoted thereafter
3. Oddy et al., 1985	▪ Severely brain injured patients and their carers ▪ N = 34 ▪ Mean age unknown ▪ PTA > 2 days ▪ Time post-injury 7 years on average	▪ Longitudinal design, patients and carers seen after two and seven years ▪ Interviews and checklists with patients and relatives	▪ Memory problems most frequently cited by carers and patients ▪ Long-term personality changes in 40% of the sample ▪ Disabilities and social relationships have changed little over five years, though improvements have occurred for a few ▪ Loneliness and social isolation were the main social problems, especially for those who were unable to work. This did not seem to have improved over the course of years.	▪ No description of the 30% of patients lost to follow-up ▪ Relatively small sample size ▪ Semi-structured interview not adequately described ▪ Not clear whether subjects are heterogenous brain injuries or just closed head injuries ▪ The relationship of the informant to the patient is not described

4. Brooks et al., 1986	▪ Severely brain injured patients ▪ no focal wounds ▪ N = 42 ▪ Mean age 35 ▪ PTA > 2 days, median 21 days	▪ Longitudinal design, patients and carers seen after one and five years ▪ Interview with close relative and questionnaires	▪ 75% of carers reported 'personality change' after 5 years, up 14% on 4 years earlier ▪ Threats of violence up from 15% to 54% ▪ 'Poor memory' unchanged in 2/3 of patients ▪ The 'top ten' items of change in the patient at 5 years are similar to those at 1 year ▪ The extent to which patient outcome was related to overall severity diminished between 1and 5 years	▪ Sample comprised patients with very severe TBI who had undergone a neurosurgical procedure. Sample is therefore not representative of the TBI population. ▪ No analyses comparing the 'lost' follow-ups' (24%) with the group that were followed up. ▪ The 'structured interview' is not described in detail
5. Brooks et al., 1987b	▪ Severely brain injured patients ▪ N = 134 ▪ Range of ages 15-70 ▪ PTA > 2 days ▪ Time post injury 2-7 years ▪ Mean age not given; Most in twenties and thirties	▪ Cross-sectional design ▪ Neuropsychological measures ▪ Questionnaires and interviews with brain injured person and close relative	▪ Before the injury 85% had been working, afterwards 71% were not. ▪ No consistent reduction in problems (physical; language; emotion; dependence; behaviour memory) between 2-7 years as reported by the carer ▪ Personality change / poor memory in 75% of the sample ▪ Psychosocial problems make a greater contribution to overall disability than physical problems ▪ Post-traumatic behavioural / emotional problems was a highly significant predictor of failure to return to work	▪ The development of the structured questionnaire is not described ▪ Sample comprised patients with very severe TBI who had undergone a neurosurgical procedure. Sample is therefore not representative of the TBI population. ▪ Method of recruitment inadequately described ▪ Time post-injury inadequately described
6. Lezak and O'Brien, 1988	▪ Severely brain injured patients ▪ N = 42 ▪ The majority has Loss of consciousness (LOC) > 2 weeks, 8 had LOC < 1 day ▪ Mean age 27.1	▪ Longitudinal design; ▪ Portland Adaptability Inventory, information from clinicians or carers ▪ PAIS filled in on 6 occasions from 6 months post-injury to 5 years post-injury	▪ Pattern of continuing difficulties: anger, anxiety, relationships, social contacts, work/school, driving ▪ Pattern of rapid improvement: initiative, living independently, leisure, ambulation ▪ Pattern of slow improvement, more variable: driving, inappropriate social interaction ▪ 3 Recovery patterns for symptoms	▪ Subjects only men: not representative ▪ Selection of subjects inadequately described ▪ Development of questionnaire inadequately described ▪ PAI scored retrospectively on the basis of notes in a few cases ▪ Sample too small to identify 3 patterns

			▪ In all time periods the areas in which impairments were most frequently noted were related to social adjustment	with confidence
7. Jacobs, 1988	▪ N = 150 ▪ Randomly selected out of 350 responders ▪ 1-6 years post-injury ▪ No data on exact severity; probably moderate to severe	▪ Cross-sectional ▪ Interview with close family member ▪ 700 item survey: wide range of general skills, e.g. self-care, mobility, cognition, etcetera	▪ A wide range of skill deficits was found among the surveyed population, ▪ Hierarchic abilities were found within life skills areas ranging from basic processes through highly complex behaviours ▪ Families reported playing a highly significant role in the daily life of the survivor	▪ Low response rate (310 out of 1700) ▪ No data on severity of injury given ▪ Validity or reliability of instrument not reported
8. Thomsen, 1992	▪ N = 31 ▪ PTA > 1 month for all ▪ 'More than 20 years post-injury' ▪ Average age not mentioned	▪ Interview with patient and close relative	▪ 61% had no friends or acquaintances ▪ 32% had marked aggressiveness or marked disinhibited sexual behaviour ▪ 42% had no specific interests ▪ 2/32 patients had work ▪ 23% had good or rather good late psychosocial outcome ▪ No patients escaped lifelong sequelae ▪ Much variation in long term outcome ▪ Late improvement of behavioural deficits did occur	▪ No description of 20% of patients lost at follow-up ▪ Some patients had open head injuries rather than closed head injuries ▪ No clear description of measures used; Rather, the author simply stated the outcome without referring to the measures ▪ Small sample
9. Dikmen et al., 1993	▪ N = 31 ▪ 102 controls ▪ Mean age 24 years ▪ PTA > weeks ▪ Time post-injury 1, 12, and 24 months post-injury	▪ Cross-sectional ▪ Subjects were administered psychosocial measures 1, 12, and 24 months post-injury ▪ Measures: SIP; Head injury symptom checklist; Function status index;	▪ At 2 years, significant difficulties remain in ambulation, independent living, financial independence, and work ▪ Only 46% returned to work after 2 years, but often not at the same level ▪ Cognitive and behavioural symptoms were highly endorsed initially and remained high or increased ▪ Physical symptoms were highly endorsed early on and decreased later on	▪ Small sample ▪ Recruitment process inadequately described ▪ Not clear to what extent sample is representative of general TBI population
	▪ 32 Severely brain injured	▪ Cross-sectional design	▪ CHI scored lower than SCI on: memory,	▪ Small sample size, especially the control

10. Alfano et al., 1993	patients ▪ Average LOC 1.3 months ▪ Average age around 30 ▪ Control group: 21 Patients with spinal cord injury ▪ Time post-injury: 3.5 years	▪ Questionnaires: depression, anxiety, own functioning inventory, behavioural health, PAIS	language, and general cognitive functioning, no differences on PAIS ▪ Striking similarities between the two groups, suggesting that poor psychosocial adjustment in TBI is not necessarily specific to this disorder but rather may represent more general features of TBI or chronic disability	group ▪ Relatively low percentage agreed to participate (55.2%)
11. Schalen et al., 1994	▪ Severely brain injured patients ▪ N = 102 ▪ PTA > 2 weeks ▪ Included patients classified as 'good recovery' and 'moderate disability' on the Glasgow Outcome Scale after 6 months ▪ Time post-injury: 5-8 years ▪ Mean age not mentioned	▪ Cross-sectional design ▪ Measures: Hopkins psychiatric symptom checklist, social adjustment scale, psychopathological rating scale (all self-report)	▪ 28% had psychiatric symptom scores against19% in a primary care sample ▪ Psychiatric symptom prevalence about 3 times higher than the American norm population ▪ Social adjustment not good in terms of social relations and leisure (40%) ▪ Only moderate difference in psychiatric symptomatology compared to primary care patients, but considerable differences with a 'normal' population	▪ Severity of head injury and time post-injury of sample not adequately described ▪ Only patients who had been admitted to the department of neurosurgery were investigated. Sample was therefore not representative of the general TBI population.
12. Witol et al., 1996	▪ Severely brain injured patients ▪ N = 60 for group that was 6.1 yeas post-injury ▪ N = 37 for group that was 15.8 years post-injury ▪ LOC > 40 days for both groups	▪ Cross-sectional design ▪ Two groups, one is on average 6.1 years post-injury, the other is 15.8 years post-injury ▪ Measures: Neurobehavioural functioning inventory, filled in by carer	▪ Means for sub-scale scores of the Neurobehavioural Functioning Inventory were not significantly different (aggression. Attention / memory, communication, depression, somatic, motor) ▪ Suggests that there may be no change over time in terms of neurobehavioural problems	▪ Biased sample: only unemployed brain injured people. Sample therefore not representative of general TBI population ▪ Group 2 (15 years post-injury) had more severe head injuries; Comparison between groups therefore difficult ▪ Sample only included people seeking rehab and this group likely constitutes persons with more problematic outcomes
13. Masson et al., 1997	▪ N = 304 ▪ Time post-injury: 5 years ▪ Mild, moderate and severe head injuries ▪ Average age: Not given	▪ Population-based study ▪ Interview ▪ European Chart for brain injured patients evaluation ▪ Analysis in terms of impairments, disabilities and handicaps	▪ Increasing number of cognitive and behavioural complaints with increasing severity, particularly in terms of slowness, irritability, anxiety, depression, memory and fatigue.	▪ Group of mild, moderate and severe head injuries ▪ Open and blunt head injuries ▪ Different methods of data collection: face to face, telephone and postal questionnaire ▪ No analysis of 25% non-responders ▪ Severity rated with the Abbreviated Injury

				Scale (AIS), not a standard measure which is much used
14. Koskinen, 1998	▪ Severely brain injured patients ▪ N = 15 ▪ PTA between 14 and 120 days ▪ 10 years post-injury ▪ Average Age: not mentioned	▪ Longitudinal design; second follow-up ▪ Methods: questionnaire for patient and carer; domain-specific life satisfaction, functional assessment scale, neurobehavioral rating scale	▪ Emotional reactions / personality / behaviour changed according to 85% of patients and 87% of carers ▪ At least 73% said they were rather satisfied, only 13% reported being very dissatisfied. ▪ Life satisfaction not related to severity, instead to anxiety, depression ▪ A high degree of physical, cognitive and emotional/behavioural disturbances remains after 10 years	▪ Small sample ▪ Selection of patients: only those who were under 40 years of age at the time of the injury and no history of previous psychiatric illness/brain injury. Sample not representative of wider TBI population. ▪ No comparison between dropouts (21%) and the group that was studied
15. Dean et al. (2000)	▪ N = 184 ▪ Mean time post-injury 15 years ▪ Severity 'moderate to severe' ▪ Average age: 30 at time of injury (45 at time of follow up)	▪ Structured and non-structured interview with brain injured person ▪ "List three main problems" ▪ Content analysis of interviews	▪ Most rated Problem areas were movement (39%), cognition (36%), sensory (31%), emotional/behavioural (24%)	▪ Sample includes general brain injuries, not just blunt head injuries ▪ Response rate and recruitment process inadequately described ▪ Severity of injury not described in terms of length of consciousness or PTA ▪ Medical Interviewer likely to have biased participant to mention 'medical' concerns
16. Zec et al., 2001	▪ 32 Severe closed traumatic brain injury patients ▪ 15 Spinal cord injury patients ▪ Normal control group ▪ Length of coma: 65.8 days ▪ Average age: 34.4 ▪ Time since injury: 10.1 years	▪ Cross-sectional design ▪ Tests: Wechsler Memory Scale, Rey Auditory verbal learning, WAIS-R, Wide range achievement test, Mini mental state exam	▪ No differences between the two control groups ▪ The CHI group scored significantly worse on all except three measures when compared to either the SCI or the control group ▪ People with CHI have significant long-term cognitive impairments, and in particular memory impairments compared to people with a spinal cord injury and a normal control group	▪ Small TBI sample size; very small size of the spinal cord injury control group ▪ Recruitment process of the TBI group, and particularly of the 'normal' controls not adequately described ▪ It was not a 'prospective, longitudinal study in a consecutive series', as the authors themselves pointed out
17. Millis et al., 2001	▪ Brain injured patients ▪ Mild to severe head injuries ▪ No clear severity data, mixed group between mild and severe	▪ Longitudinal design ▪ Recovery of cognitive function between 1 and 5 years post-injury ▪ Measures: a wide range of neuropsychological measures	▪ Improvement from 1 year after injury to 5 years was variable: 22.2% improved, 15.2% deteriorated, and 62.6% were unchanged on test measures ▪ Improvement was most apparent on measures	▪ Severity of head injury nor clearly described, is a mixed group of mild and severe head injuries ▪ The 'mild' group not likely to be representative of most persons with mild

	▪ N = 182 ▪ Mean age at 5 years post-injury: 39		of cognitive speed, visuo-construction and verbal memory ▪ Recovery may continue for a subset of brain injured people, but most either stay the same or deteriorate. ▪ Recovery may occur beyond the 6 to 18 months period for some people	TBI because they required both acute hospitalisation and rehabilitation ▪ Sample sizes for comparing neuropsychological tests between 1 and 5 years ranged from 35-96. Substantial amount of missing neuropsychological test data ▪ No comparison between drop-outs and those who stayed in the study ▪ Those with continuing impairment were more likely to return for follow-up. Comparison of groups is therefore difficult. ▪ Many of the tests used in the study were not normed in the same sample
18. Steadman-Pare et al., 2001	▪ 286 Brain injured patients ▪ Moderate to severe head injuries ▪ Mean age: 43 years ▪ Time since injury: 14 years	▪ Cross-sectional design ▪ Measures: physical functioning, SF-36, self-rated health, degree of handicap/participation, severity of residual cognitive deficits, social support, subjective quality of life	▪ Subjective quality of life was related to: mental health, self-rated health, gender (women rating QOL higher), participation in work and leisure, and the availability of emotional support ▪ Psychosocial factors were strongly related to QOL ▪ The importance of ongoing support programs to further integrate TBI survivors into society is needed	▪ Sample is a mixed group of blunt head injuries and other brain injuries; Not representative of general TBI population ▪ "Small percentage" of interviews were done by telephone
19. Hoofien et al., 2001	▪ N = 76 ▪ Mild to Severe TBI; average length of coma 14 days ▪ 14.1 years post-injury ▪ Average age: 38.6 years	▪ Cross-sectional ▪ Measures: SCL-90; post-traumatic stress disorder inventory; behaviour evaluation checklist; acceptance of disability questionnaire; WAIS-R; Rey test; WMS-R; Peg board test; Family functioning; social functioning; independence;	▪ Psychiatric symptomatology elevated, incl 'hostility, depression, anxiety, psychoticism, obsessive-compulsiveness, somatisation, and phobic ideation ▪ Significantly fewer of the brain injured sample were married than the national average while the divorce rate is higher ▪ Participants rated their social functioning lower than any other domain; 31% reported they had no friends at all	▪ Sample of patients attending a neuropsychological rehabilitation centre. Not representative of the general TBI population. ▪ Recruitment process not adequately described ▪ Sample also includes people who were not in a coma, i.e. sample is a 'mixed bag' of mild to very severe head injuries ▪ Use of national data and norms rather than a control group

1.6.1. Critical evaluation of long-term outcome studies

It is clear that two decades of research into the long-term cognitive and psychosocial consequences of severe head injuries have taught us much about the type and the persistence of the cognitive, behavioural and social sequelae. This will be discussed in the next few sections. But what about the quality of the studies? This section will briefly evaluate critically some of the methodological inadequacies of the studies in the table above. The following points can be made:

- It is fairly surprising to see that with the notable exception of a very few (e.g. Witol et al., 1996; Zec et al., 2001), most authors do not critically evaluate their own research. It should be standard practice to state the limitations of the conclusions drawn from the study.
- Most studies are single-sourced, i.e. either the patient himself or a close relative is asked to give information. Information coming from either source is biased (see chapter 4), and it would therefore be preferable to use multiple sources of information or triangulation in order to improve the reliability of the results.
- There are a number of studies which have very small sample sizes (e.g. Koskinen, 1998). Related to this issue, when there is a comparison between the brain injured group and a control group, none of the studies reports having performed any kind of power analysis to determine the number of participants needed to be able to draw valid conclusions.
- In longitudinal studies, it is questionable to compare a group of brain injured people who were treated at a rehabilitation centre with the same sample who returned (for clinical reasons, rather than for research purposes) a number of years later to a rehabilitation centre (e.g. Millis et al., 2001). This is because clinicians tend to stay in touch with those patients who continue to experience difficulties, making the comparison between groups unreliable.

Witol et al (1996) have a similar problem, despite the fact that their study is cross-sectional. In their study, two groups are compared in terms of the neurobehavioural

functioning inventory. However, it can be argued that those brain injured people who are still seen by the clinicians at their rehabilitation centre are more likely to experience difficulties and this makes comparison with the group that is closer to the injury in time difficult.

- There was no comparison between drop-outs or non-responders and those who stayed in the study, except in Steadman-Pare et al.'s (2001) study. Some described the patients who dropped out (e.g. Brooks, 1987b), but only one actually compared them in terms of early demographic or psychosocial variables. Steadman-Pare et al. (2001) suggested that non-responders did not differ from responders in terms of severity of the injury, but were more likely to be men and divorced, separated or widowed at time of injury.
- Most studies are uncontrolled clinical samples, i.e. patients admitted to particular hospitals or rehabilitation centres, rather than *community based* samples. Selecting patients this way introduces a major selection bias. Most samples studied are therefore not representative of the general TBI population.

1.6.2. Long-term cognitive effects of severe traumatic brain injury

Wilson et al. (1991) showed that some 60% of severely brain injured people (both 'open' and 'blunt' head injuries) did not show any improvements in memory function when followed up 5-10 years later. One third did actually improve in terms of memory functioning. Zec et al.'s (2001) research design included a control group, namely 21 patients with spinal cord injury (SCI). The use of SCI groups is often recommended as a control group for research into the effects of traumatic brain injury. Both TBI and CHI groups are likely to share a variety of possible pre-injury characteristics associated with being at risk for injuries caused by serious accidents, especially motor vehicle accidents. An SCI group also helps to control for post-injury factors associated with having sustained a serious injury and disability. The TBI group displayed significantly poorer performance than the SCI group on every measure of memory, and the effect sizes were large. These impairments clearly show long-term new learning and retention deficits in this TBI group which is independent of any pre-injury or post-injury differences. Millis et al., (2001), shed more light on the course of cognitive recovery in a

longitudinal study. They tested 182 people with mild to severe head injuries one and five years post-injury and performed a wide range of neuropsychological tests. Unfortunately, they did not give clear data on the severity of their sample, but it was severe enough to warrant inpatient rehabilitation. They used a procedure called 'the reliable change index' in order to calculate the number of people who made a significant change compared to the assessment 4 years earlier. Using this method, they found that overall, 22.2% of their sample improved in terms of overall cognitive functioning, 15.2% deteriorated, and 62.6% were unchanged on test measures. In the subgroup of brain injured people who improved, improvement was most apparent on measures of cognitive speed, visuo-construction, and verbal memory. This study clearly shows that, although for most brain injured people their cognitive status will actually not improve, and sometimes even deteriorate, there is clearly a small sub group of brain injured people whose cognitive status does improve. It therefore also shows that cognitive improvement is possible beyond the 6-18 months mark which is usually mentioned.

1.6.3. Long-term perceived cognitive, behavioural and emotional effects of severe traumatic brain injury

Most long-term outcome research has been conducted using questionnaires or interviews with both the brain injured person and a close relative as the main informers. The first studies were conducted in Denmark, England and Scotland, and the United States followed.

A number of cognitive effects have frequently been mentioned. Table 1.3. shows a number of cognitive effects reported by a close relative of the brain injured person. Details of each study are shown in table 1.2.

Table 1.3. Three cognitive consequences of TBI as reported by a close relative (or patient when indicated)

	Memory	Concentration	Slowness
Van Zomeren, 1983			
2 years post-injury	53%	33%	33%
(Report by patient)			
Thomsen, 1984			
2-5 years post injury	80%	73%	65%
10-15 years post-injury	75%	53%	53%
Oddy et al. 1985			
7 years post injury	79%	50%	
Brooks et al., 1986			
1 year post injury	67%		65%
5 years post injury	67%		67%
Brooks et al. 1987			
7 years post injury	76%	64%	77%
Dikmen et al., 1993			
2 years post-injury	61%		

Table 1.3 shows that between half and three fourth of the close relatives report long-term consequences in terms of memory, concentration and slowness.

Table 1.4. shows emotional changes, behaviour problems and personality changes as reported by a close relative.

Table 1.4. Long-term emotional, behavioural, and personality changes as reported by a close relative

	Personality Change	Anger/ irritability	(threats of) violence	Childishness	Depression	Anxiety
Thomsen, 1984						
2-5 years post injury	80%	38%		60%		
10-15 years post-injury	65%	48%		25%		
Thomsen, 1992						
20 years post injury		32%				
Oddy et al. 1985						
7 years post injury		43%		40%		
Brooks et al., 1986						
1 year post injury	60%	67%	15%		51%	57%
5 years post injury	74%	64%	54%		57%	57%
Brooks et al. 1987						
7 years post injury	76%	74%			63%	65%
Dikmen et al, 1993						
2 years post-injury		50%				
Koskinen, 1998						
10 years post injury	87%					

Table 1.4 shows the persistent nature of many personality changes, behaviour problems and emotional problems. Between 60 and 87 percent of all close relatives report long-term personality changes, including (for many) anger, irritability, threats of violence and childishness. A further 51-54 percent reported long-term anxiety or depression.

Witol, Sander, Seel, and Kreutzer (1996) compared two groups of severely brain injured people in terms of their neurobehavioral characteristics. The first group (N = 60) was on average 6.1 years post-injury, while the second group (N = 37) was on average 15.8 years post-injury. The two groups were compared in terms of the ratings on the Neurobehavioral Rating Scale (see section 5.3.4.3. and appendix 5.4.) of a significant other. There was no difference between the groups in terms of the sum-scores (aggression; attention/memory; communication; depression; somatic functioning; and motor functioning). Table 1.9. lists the most frequently endorsed neurobehavioural problems. There is a high degree of similarity between items mentioned by

these two groups. The results of this cross-sectional study suggest that there may be very little change in functioning over time.

Table 1.5. Most frequently endorsed neuro-behavioural problems (Witol et al., 1996)

Symptom	Mean	Symptom	Mean
GROUP 1 (6.1 years post-injury)		**GROUP 2 (15.8 years post-injury)**	
bored	2.57	frustrated	2.44
moves slowly	2.54	forgets what he/she reads	2.38
frustrated	2.40	impatient	2.33
difficulty lifting heavy objects	2.33	misunderstood by others	2.33
writes slowly	2.30	bored	2.28
reads slowly	2.34	loses train of thought	2.27
poor concentration	2.27	reads slowly	2.27
trouble making decisions	2.33	writes slowly	2.24
tired	2.30	moves slowly	2.22
thinks slowly	2.27	tired	2.29
loses train of thought	2.24	thinks slowly	2.29
easily distracted	2.21	difficulty thinking of the right word	2.17
impatient	2.20	restless	2.17
loses balance	2.16	trouble making decisions	2.17
misunderstood by others	2.14	trouble following instructions	2.11
		learns slowly	2.11

Lezak and O'Brien (1988) followed a group of brain injured patients (N = 33). Scores were obtained on six different occasions, from 0-6 months after the accident until 5 years post-injury (N = 23). Most patients had been in a coma for more than two weeks and the mean age of the sample was 27 years. Three patterns of recovery emerged. First, a pattern of continuing problems was observed for 'anger', 'anxiety', 'significant relationships', 'social contacts', 'work / school', 'driving, and 'appropriate social interaction'. These continued to be a problem for more than one third of the patients in the fifth year. Social contacts and work / school remained a problem for the majority of the patients.

The second pattern contained problem areas which improved rapidly over time, such as 'initiative', 'independent living' (residence and self-care), 'leisure activities' and 'ambulation'.

The third pattern consisted of problem areas in which improvement was slower, more variable over time, or of less magnitude, such as driving problems, inappropriate social interaction, anger, and depression.

Twelve to twenty eight percent of the sample exhibited behaviour for which they received psychiatric diagnoses.

Schalén, Hansson, Nordström, and Nordström (1994) looked at psychiatric and social consequences in a group of severely brain injured people (N = 102) 5-8 years post-injury. They had been classified as having made a good or moderate recovery after six months, according to the Glasgow Outcome Scale. Brain injured people had slightly more psychiatric symptoms than a sample of people in primary care (N = 388). Twenty eight percent had psychiatric symptom scores on the Hopkins Symptoms Checklist indicating need of treatment, against 19 % of primary care patients. The symptom prevalence was about three times as high as the American norm sample.

1.6.4. Long-term social effects of severe traumatic brain injury

Thomsen (1984) claimed that 60% of close relatives report 'loss of social contact' after 2-5 years post-injury and 68% of close relatives report it 10-15 years post-injury. Thomsen concluded that "*loss of social contact remained the patients' most disabling handicap in daily life*" (p.267). Oddy et al. (1985) report similar results. Loneliness and social isolation were the main social problems, especially for those who were unable to work. This did not seem to have improved over the course of years. Those who were employed had managed to have a social life and even to get married. On the whole, the impression was that "*....disabilities and social relationships of the patients have changed little over a further five years, though improvements have occurred for a few - mainly those who had already made good progress at the two year stage*" (Oddy et al., 1985, p. 566). Schalen et al.'s study (1994) also showed that social adjustment of their group of brain injured people was less good in the areas of social relations and leisure. And finally, Lezak and O'Brien (1988) concluded: "*...in all time periods the areas in which impairments were most frequently noted were related to social adjustment...*" (p. 460).

Alfano, Neilson, and Fink (1993) compared a group of severely brain injured patients (N = 32; 25 male, 7 female) with a group of people with spinal cord injury (N = 19; 14 male, 3 female) in terms of their psycho-social outcome. The groups were, respectively, 3.4 and 5 years post-

injury. Similar reductions in socio-economic and employment status were found. Also, no differences were found on any of the sub-scales of the Psycho-social Adjustment to Illness Scale (PAIS). The brain injured group scored significantly higher on depression, and self-reported memory, language, and other cognitive problems. Self-perceived memory problems were especially found to be related to poor psycho-social adjustment. Overall, however, there were striking similarities between the two groups, suggesting that poor psycho-social adjustment in traumatic brain injury is *"...not necessarily specific to this disorder, but rather may represent more general features of traumatic brain injury or chronic disability"* (p. 123).

Hoofien et al (2001), in a study investigating cognitive and psychosocial consequences of mild to severe head injuries (N = 76) found that participants and family members evaluated their social functioning lower than any other domain evaluated. 31% reported they did not have any friends at all. Thomsen (1992) found that 61% of her sample reported they did not have nay friends. Social functioning of participants was also significantly related to psychiatric status (but not their intellectual abilities).

1.6.5. Summary

The above review of studies into the long-term neuro-behavioural and psycho-social outcome of severe traumatic brain injury shows that the effects can be persistent and penetrate many domains of the brain injured person's life.

A number of longitudinal and cross-sectional studies have shown that several consequences of traumatic brain injury are mentioned very often and do not seem to pose any fewer problems later in life (Thomsen, 1984; Oddy et al., 1985; Brooks et al., 1986, 1987; Lezak and O'Brien, 1988;; Witol et al., 1996; Millis et al., 2001; Zec et al., 2001). These consequences are: perceived cognitive problems (forgetfulness, concentration, slow reading, writing and thinking, trouble making decisions), emotional problems (anger, frustration, irritability and bad temper, depression, anxiety, rapid mood changes, boredom), changes in personality (aspontaneity, childishness, disturbed behaviour, threats of violence), and social maladjustment. Social outcome is reported to be the patient's main problem area by a number of authors (Thomsen,

1984; Oddy et al., 1985; Brooks et al., 1987; Lezak and O'Brien, 1988). This would suggest that what is important for a person with traumatic brain injury is not so much the fact that he has physical problems, cognitive impairments or other disabilities, but the impact these may have on employment, social relationships and social interactions. Poor social outcome may be at least partially illness-specific and not traumatic brain injury-specific, as shown by a comparison in long-term outcome between patients with spinal cord injuries and patients with head-injuries, although the sample size in this study is small (Alfano et al., 1993).

Recovery over time is possible for a sub group of brain injured people, even beyond 1 year post-injury (Wilson, 1991; Millis et al., 2001). However, most studies show that changes in behaviour, personality and social functioning are persistent.

1.8. GAPS IN THE LITERATURE

Even though knowledge of the consequences of traumatic brain injury has advanced enormously over the last three decades, there are still areas of research which have not been fully or properly investigated yet. Crisp (1993) identified a number of limitations of research into the consequences of traumatic brain injury.

Firstly, many researchers have focused on adjustment at a fixed moment in time rather than upon the process of psychological adaptation.

Secondly, most studies reflect the influence of the medical model in so far as they have focused primarily on physical and neuropsychological analyses of deficits. A direct consequence of this is that no attention has been given to the 'person as a whole', how the person is functioning in relation to the world. This includes any problems the person may have, but it also includes aspects of a person's functioning that *are* going well.

Thirdly, their results have often been based upon data obtained from structured clinical assessments and have not always yielded information that could be applied to many social (non-clinical) situations. Knowledge of the way a person has changed in terms of impairments, disabilities, and handicaps may not be relevant in the context of the brain injured person's life.

Fourthly, many researchers have utilised the reports of relatives and rehabilitation professionals with more confidence than the self-reports of persons with traumatic brain injury.

Fifthly, much of the previous literature has not acknowledged that living with a disability carries a variety of meanings, and occurs in different situations, for different individuals. Teuber (1960) observed that there is "....*almost unbelievable variety in post-injury adaptation*....". To capture this variety, one may need to go beyond neuropsychological assessment and questionnaire data. Qualitative research is very rare in the field of outcome following traumatic brain injury, with only a few exceptions (Crisp, 1993; Willer, Allen, Liss, and Zicht, 1991). These studies tend to be on a small scale.

A number of limitations of the current literature can be added to Crisp's list.

Teuber (1960) distinguished between the hard and the soft view of the consequences of brain injury. The hard view focuses on the effects which are determined by the site, extent, and nature of the lesion. The soft view, on the other hand, states that the effects are tempered, if not determined, by the nature of the person who sustains the traumatic brain injury. The number of studies looking at non-neurological factors influencing the rehabilitation process has grown, both in terms of research (e.g. Moore and Stambrook, 1992; Malia, Powell, and Torode, 1995) and theory (Kendall and Terry, 1996). However, more research is needed, especially in light of the suggestion that "*non-neurological factors might contribute to the understanding of variation in psycho-social outcome among the CHI population*" (Kendall and Terry, 1996, p. 107).

Closely related to this topic is the question of how to evaluate outcome. Most studies have looked at outcomes as objective factors or constructs which are assumed to be important for the patient. It seems that subjective approaches, in which the patient is allowed to evaluate his own life, have been neglected in evaluating outcome following traumatic brain injury, in contrast to other fields, such as mental illness (Endicott, Nee, Harrison, and Blumenthal, 1993), cancer research (Baker, Curbow, and Wingard, 1992), stroke (Viitanen, Fugl-Meyer, Bernspång, and Fugl-Meyer, 1988), Parkinson's disease (MacCarthy and Brown, 1989), spinal cord injury (Fuhrer, Rintala, Hart, Clearman, and Young, 1992), chronic illness (Felton and Revenson, 1984), and illness in general (Beaufait, Nelson, Landgraf, Hays, Kirk, Wasson, and

Keller, 1992; Ruta and Garratt,1994).

To summarise, many studies have failed to focus on factors that are relevant for the patient, have failed to look at the adjustment process underlying outcome, and have failed to look at the client's own perception of his situation into account. This study is an attempt to remedy some of these gaps in the literature.

CHAPTER TWO Traumatic Brain Injury as a Critical Life Event

2.1. INTRODUCTION

This chapter will introduce the concept of a traumatic brain injury as a critical life event, as opposed to the perception of a traumatic brain injury as a purely neurological event.

The psycho-social effects of critical life events, such as chronic illness or the loss of a loved one, have become a major focus of research in clinical and social psychology. It is proposed in this chapter and the next, that adjustment to the limitations following severe traumatic brain injury may also be looked at from that perspective.

2.2. BACKGROUND

Research into life events and life crises has been influenced by four approaches (Moos, 1982; Moos and Schaefer, 1986): a) evolution and its implications for communal and individual adaptation; b) psychoanalytic concepts and human growth theories; c) a life-cycle approach to human development; and d) interest in coping behaviours under extreme stress. Of particular importance to the development of the field have been Canon's formulation of the fight-or-flight response (Canon, 1932) and Selye's work on the General Adaptation Syndrome (Selye, 1976). Life events include normal changes which occur in most people's lives, such as marriage, change of social role, or the death of someone close, and more unusual and extreme experiences, such as specific illnesses and natural disasters (Thoits, 1983). Reese and Smyer (1983) reviewed the literature on life events and came to the conclusion that more than 35 dimensions have been used to define life events. These can be classified along three research traditions (Brim and Ryff, 1980; Theorell, 1992).

One tradition focuses on characteristics of the event itself. For example, the context in which the event occurs (e.g. family, health, work, love and marriage), the onset (sudden or gradual), the cause, or the prevalence. Holmes and Rahe's (1967) classification of events in terms of the extent to which they are likely to produce stress is a typical example of this tradition. A problem with this absolute 'event' approach is that there is evidence that the correlation between the severity of life events and psychological or psycho-social stress is only modest (Thoits, 1983). People tend to respond differently to the same potentially stressful situation. Also, an event cannot be a crisis until it is recognised as such by the victim.

In view of the above criticisms, it is no surprise that a second tradition stresses the individual's perception or evaluation of the event as important in determining outcome. Examples of relevant dimensions include the amount of control the person experiences, the desirability, familiarity and meaning of the event, perceived loss, and the long-term threat.

A third tradition focuses on the outcomes or consequences of events (Brim and Ryff, 1980). For example, the amount of change and the domain in which change occurs.

An obvious combination of these positions states that an event is more likely to be perceived as a crisis when it has actually caused a disruption to a person's life, and when the event itself has certain characteristics.

In the remainder of this chapter, the focus will be on crises within a particular context (health) and on a particular type of event (the perception of loss).

If one extends the life event concept into the specifically medical domain, there are different types of disease or conditions which could be characterised as critical life events. These include:

- Terminal diseases (e.g. Alzheimer's disease; malignant tumours);
- A single event which has long-term consequences (e.g. spinal cord injury; traumatic brain injury);
- Continuous events (e.g. arthritis; chronic pain);

Death or illness of someone who is close will also be included in this review, because a life event approach to these conditions and events illustrates clearly that despite their apparent differences in symptomatology and origin, they do have factors in common, so that it can be said that "*...a common psychological process underlies the reactions of victims, regardless of their victimisation*" (Janoff-Bulmann and Schwartzberg, 1991, p.495). They can therefore all be labelled 'critical life events'.

2.3. WHAT IS A CRITICAL LIFE EVENT?

Janoff-Bulman and Schwartzberg (1991) argued that people have basic assumptions that enable them to make sense of their world and that guide their behaviour. These assumptions consist of ideas about the self and one's place in the world. They also include certain illusions about the self, such as the illusion of control, over-optimism, over-positive views about one's self (Weinstein, 1980; Taylor, 1983; Taylor and Brown, 1988; 1994) and the meaningfulness and benevolence of the world (Janoff-Bullman, 1985). Trauma challenges these stable basic assumptions about oneself and the world.

Trauma can be defined along two lines (Janoff-Bulman and Schwartzberg, 1991). Firstly, the depth or breadth of change refers to the extent to which the traumatic event forces a re-evaluation of basic assumptions. Global assumptions about oneself ("*I am a good person*") are more difficult to change than more specific assumptions ("*I am a good piano player*"). Taylor (1995) made a similar claim: people are more vulnerable to stress in central life domains than in peripheral ones. Secondly, change may have to occur either gradually or as a result of a sudden, unexpected event. Unexpected events have been associated with more psychological distress and depression (Thoits, 1983). Most dramatic and traumatic are changes that are deep and which occur suddenly and unexpectedly (Janoff-Bulman and Schwartzberg, 1991). Moos (1982) proposed a similar idea. Acutely ill patients face hospitalisation, permanent changes in function or appearance, the loss of control and social roles, a perception of discontinuity in their life, and an uncertain future. Moos argued that what turns an illness into a health crisis is the "*sudden and unexpected onset and the pervasive threat to the essence of an individual's life and adaptation*" (Moos, 1982, p. 130).
Some authors stress the importance of replacing 'old' assumptions with 'new' ones, and the painfulness of this process.

Wortman and Silver (1992) suggested that critical life events involve permanent change, over which people have little or no control. This affects a person's 'homeostasis': the mind's ability to maintain stable models of self and the world (Horowitz, 1979). Stress and imbalance occur because one model of self and others needs to be replaced by another model. The discrepancy between existing schemata and new information leads to an emotional reaction. Becker (1993) put it slightly differently. She described the onset of chronic illness as a disruption of continuity. Mechanisms to regain a sense of continuity are immediately activated. Patients "*face the task of integrating the profound physical and biographical disruptions that have occurred into their self-image so that a continuous sense of self emerges*" (Becker, 1993, p. 148). In her study on patients in old age recovering from stroke, Becker found that being unable to accomplish this integration leads to maladjustment. In his book on bereavement, Parkes (1996) argued that changes are part and parcel of normal life. What links all these changes is the fact that the old environment needs to be given up and the new environment must be accepted. When change is perceived as something negative, people will have difficulty giving up the old environment. The basis of maladjustment and grief is *"resistance to change, the reluctance to give up possessions, people, status, expectations*" (Parkes, 1996, p. 11). When it is too difficult for the person to change, he will adopt a 'flight' approach. Instead of facing the necessary changes head on, he will avoid them, not listen to sensible advice, and hang on to old ideas and assumptions. Moos and Schaefer (1986) summarised the 'disruption-of-normal-schemata-and-behaviour' aspect of a crisis as follows:

"Similar to the requirement for physiological homeostasis, individuals have a need for social and psychological equilibrium. When people encounter an event that upsets their characteristic pattern of thought and behaviour, they employ habitual problem-solving strategies until a balance is restored. A crisis is a situation that is so novel or major that habitual responses are insufficient; It leads to a state of turbulence typically accompanied by heightened fear, anger, or guilt. Because a person cannot stay in a state of disequilibrium, a crisis is necessarily self-limited. The new balance may be a healthy adaptation that promotes personal growth or a maladaptive response that foreshadows psychological problems. Thus, a crisis is a transition or turning point that has profound implications for an individual's adaptation and ability to meet future crises" (p. 9)

The most widely used categorisation of life events has been the desirability of the event (Cohen, 1988; Taylor, 1995) or perceived personal loss of normal functions (Theorell, 1992). This can be

investigated as a personal, subjective evaluation, or as a normative event. It has been generally found that psychological distress is more related to the undesirability of loss/change than to the absolute amount of loss/change (Thoits, 1983).

Shuchter and Zisook (1993) described an enormous sense of loss in the context of death and bereavement. It is "*the sense that one has lost something essential that cannot be retrieved*" (p. 28). This is turn leads to negative emotions (such as anger, guilt, regret, depression, and anxiety), and to the questioning of the self, roles, way of living, sense of meaning, and visions of the future. Shuchter and Zisook (1993) stressed the multidimensional nature of reactions to loss and grief. They found that bereaved spouses show cognitive and emotional responses, coping responses, a continuing attachment to what has been lost, behavioural changes, social changes, and changes in identity.

The next most widely used definition of life events has been in terms of the controllability (Thoits, 1983; Cohen, 1988; Taylor, 1995). The concept of control has been used in the context of learned helplessness (Seligman, 1975). In the case of life crises, 'control' can refer to the cause of the crisis, for example, 'tumour' or 'car accident'. Uncontrollable events are perceived as more stressful than controllable events (Taylor, 1995). Uncontrollable events are associated with depression (Thoits, 1983) and are related to a longer stay in the hospital for accident victims (Frey, 1991) than more controllable events. 'Control' can also refer to the subsequent effects of the crisis on the person's perception of control. For example, a person with permanent injuries may feel that he lacks control over his own destiny.

2.3.1. Summary

Choosing a definition of a critical life event, is ultimately arbitrary and depends on the interests of the investigator (Brim and Ryff, 1980; Sugerman, 1986). Filipp (1992) proposed a definition which contains most of the issues suggested in the literature. He described the diagnosis of cancer as a prototype of a critical life event and argued that there are certain characteristics which turn a life experience into a 'critical life event':

1. Threats to life and health represent existential plights and arouse extremely strong negative emotions.
2. They are beyond the control of those suffering from them.

3. They interfere with goals that people have set for themselves for the future.
4. They are a threat to fundamental beliefs and assumptions about the self.

An additional, essential aspect of a critical life event appears to be the inadequacy of 'old' models of the self and the world and the need to integrate a new reality into one's existing perceptions.

How may the effects of traumatic brain injury be viewed in the context of the literature on critical life events? This will be the subject of the next section.

2.4. TRAUMATIC BRAIN INJURY AS A CRITICAL LIFE EVENT

Until recently, traumatic brain injury has not been considered from a critical life event perspective. Attention has focused on the direct effects as a result of the brain damage and on 'final' levels of impairments, disability, and handicap. The danger of focusing on 'final' levels of disability is that clinicians may feel that no further rehabilitation is feasible and/or required.

In this section, it is proposed that a severe traumatic brain injury is a critical life event. Treating a traumatic brain injury as a critical life event has certain consequences, which will be detailed in chapter three and four.

Research on the impact of a traumatic brain injury on a person's psychological functioning is rare, but not completely absent (e.g. Willer et al., 1991; Crisp, 1993; Keen, 1995). Many publications report individual cases and anecdotes, or have been written up from clinical experience (Teuber, 1960; Harrell and O'Hara, 1991; Prigatano, 1989, 1991, 1994, 1995; Lewis, 1991; Nadell, 1991; Bennett, 1987; Zahn and Littman, 1989; Klonoff and Lage, 1991; Miller, 1993; Powell, 1995). Prigatano (1991) and Lewis (1991) suggested a number of reasons for the disregard of counselling approaches to traumatic brain injury, which may also apply to the relative disregard of psychological approaches to traumatic brain injury in general.

Firstly, an assumption that brain injured patients would not benefit from counselling because of their permanent cognitive, linguistic, and emotional disturbances.

Secondly, neurologically and neuropsychologically oriented psychologists have found it difficult to combine the language of neuroscience with more subjective approaches.

Thirdly, the vagueness of defining psychotherapy.

Fourthly, an underestimation of just how much brain injured patients struggle with the same problems as healthy people or people with other disabilities.

Prigatano (1989) and Crisp (1993) suggested that traumatic brain injury produces an abrupt transition in life. Physical, cognitive, emotional, behavioural, and social changes may occur. Even very small lesions in the brain can produce changes which may not even be picked up by psychometric testing. Functions are permanently changed, and the patient may not always recognise and understand these changes because of a lack of awareness (Prigatano, 1995). There may have been changes in their view of the world, of others, and themselves (Harrell, 1991). Social networks often become smaller and social support has decreased after the accident (Oddy, 1984; Kozloff, 1987; Holosko and Huege, 1989; Leach, Frank, Bouman, and Farmer, 1994; Zencius and Wesolowski, 1999). Taking all this together, it means that brain injured patients have to deal with the changes from a pre-injury state to a post-injury state (Prigatano, 1995). A similar idea was expressed by Harrell (1991): "*Each survivor must come to terms with personal losses and integrate new aspects of the post-injury self into the pre-injury self-concept. The survivor may need to drastically alter life goals as a result of the injury...*" (p. 12). 'Homeostasis' has been destroyed following a severe traumatic brain injury (Zahn and Littman, 1989). A common observation by survivors is that "*things are not the same*" (Bennett, 1987). An inability to reconcile loss of self and an inability to integrate new information about how the person has changed is a major determinant of depression (Zahn and Littman, 1989).

Zahn and Littman (1989) stated that the brain injured person faces three tasks:

1. Permit the idealised integrated identity of the past to die, and mourn its loss
2. Sort out the elements of personality that are relatively intact and functional from those fragments that are no longer useful
3. Give up the fantasy of a fully restored, 'better than ever' personality

Following their accident, brain injured patients often ask themselves three existential questions (Prigatano, 1991; 1994b; 1995).

The first question people ask is: "Why did this happen to me?" (Prigatano, 1991; Girard and Schadelle, 1975). Brain injured patients try to make sense of the experience. In the case of traumatic brain injury, this may be a very difficult process because the person often cannot remember exactly what happened. He has 'lost' a considerable period of time in his memory

because of the post traumatic amnesia. This period of time needs to be filled in by people who have been with the patient throughout the recovery. Also, in some cases, the person is not to blame for the accident, so that there is no specific reason why the accident should have happened to him in the first place.

The second question people who have sustained a traumatic brain injury ask is: "Will I ever be normal again?" Pre-injury, the patient was going in a certain direction in his/her life. They will want to go in the same direction after the accident, but for many this is no longer possible because of all the changes (Prigatano, 1994a).

The third question is: "Is life worth living after brain injury?" How can life have a purpose and a meaning despite the presence of impairments, disabilities, and handicaps? Changes in vocational status, social relationships, social roles, and recreation may have shaken the basis of one's assumptions about oneself and the world (Nadell, 1991). Only by entering the person's phenomenological experience can any maladjustments be understood (Prigatano, 1994).

Keen (1995) reported on feelings of loss and grief in a group of 200 brain injured people. Table 2.1 Lists a number of common responses. He found that grief reactions and grief behaviour are very common following traumatic brain injury. He stated that therefore "*emotional and behavioural features following traumatic brain injury are not exclusively the consequence of physical damage to the brain itself, but also comprise a wider psychological based 'true grief' reaction, experienced by people who are aware of what they have lost and how fundamentally their lives may have changed*" (p. 13).

Table 2.1. Percentage of people responding with 'definitely applies to me' to statements concerning grief responses (Keen, 1995)

Grief response	**%**	
I could not believe that I had lost some of my abilities for good	49	
I did not find it easy to come to terms with the way I had changed	54	
I have returned again and again to thoughts of what I was like before		33
I often think about what I was like before	38	
I kept on searching for the part of me that was lost		34
After my traumatic brain injury I felt like I was not the person I was before	58	
I felt like I had to learn about myself all over again		46
After my traumatic brain injury, I felt like a stranger to myself	40	
After my traumatic brain injury I felt like I had lost something important in my life	60	

Tyerman and Humphrey (1984) asked a group of 25 severely brain injured people to rate themselves on a personality scale the way they were before the accident and the way they are now. Overall, the brain injured persons rated their present self significantly different than the past self on 17 out of 20 items, confirming that "*patients viewed themselves as having changed substantially on a wide range of constructs*" (Tyerman and Humphrey, 1984, p. 19).

Self-observations by brain injured people following traumatic brain injury are useful, because they can provide an insight in the insider's perspective: what it is like to have sustained a traumatic brain injury. Many people have written about their own particular experiences after having sustained a traumatic brain injury (e.g. Campbell, 1987; Weidner, 1986; Dann, 1984; Perry, 1986; Linge, 1992; Hill, 1997; Osborn, 1998). 'Loss' is a central concept in these stories. Dann (1984) stated "*my perception of loss has been shaped by an experience which forced me to re-evaluate my entire definition of self*" (p.11). Hill (1997) felt that she had to come to terms with a new identity of being disabled. Campbell (1987) felt a "*deep, general sense of loss of wholeness and well-being*" (p. 206). Aspects of one's life that used to be taken for granted (such as going up the stairs, eating, and remembering) have become almost impossible tasks. This prompted Campbell (1987) to state that "*most of the ways I had for defining myself as a good person were gone*" (p. 206). The changes also force a person to change plans and long-term goals. Giving these plans for the future up can be a long and painful process. "*I have to realise that I am a different person now, but it's hard*" (Weidner, 1986, p. 4).

2.5. SUMMARY

The researcher is very much aware of the fact that many new and promising developments have taken place in the field of rehabilitation of brain injured people since the ideas in this thesis were first conceived of. Many of these developments are described in McMillan and Wood (2002). Of particular importance is the setting up of specific traumatic brain injury community teams (e.g. Tyerman, 1999) which are now thought to be an integral part of long-term rehabilitation of brain injured people (McMillan and Oddy, 2002). Specialised clinicians often provide services in cognitive behaviour therapy (e.g. Beaumont, Connolly, and Rogers, 1999; Manchester and Wood, 2002) in these teams, as advocated in the discussion section of this thesis.

Traumatic brain injury is the result mainly of road traffic accidents, falls, and assaults. As shown in Chapter one, the effects can be severe and persistent. There are similarities between having sustained a traumatic brain injury and, for example, being diagnosed with cancer or losing someone who is dear. For the person who sustains a traumatic brain injury, it is an unexpected event. Also, they often have no control over the particular event. Even if they themselves are to blame for what has happened, they do not remember the actual incident and experience a lack of control in that sense. People with a severe traumatic brain injury are often faced with a whole new reality: cognitive and physical impairments, the loss of a job and leisure activities, changes in relationships with other people, and a different future from what they had in mind. They can experience a strong sense of loss for the faculties that were intact before the accident. This evokes strong negative emotions and the forces the person to change the individual's perception of him- or herself to adjust it to a new reality.

Considering this, it is becoming clear that severe traumatic brain injury fits the criteria set out by Filipp (1991) and that it can be labelled as a critical life event.

CHAPTER THREE Adaptation to Critical Life Events

3.1. INTRODUCTION

It was established in chapter two that traumatic brain injury can be classified as a critical life event. It was argued that different types of life events have factors in common, so that they can be called critical life events. The same logic is applied to the adaptation process following critical life events. Implicit in the concept of critical life events is the fact that they require adaptation. Because the psychological impact of different events is very similar, the case can be made for similarities in the adaptation process as well. For example, Parkes (1996) suggested that there is a similarity in psychological reactions after bereavement, amputations and house relocation. If, as argued above, traumatic brain injury can be understood as a critical life event, it follows that the wealth of literature on the way people adapt to or deal with life events, such as physical disability, chronic illness, or bereavement can be used to examine the way people deal with the consequences of traumatic brain injury.

3.2. BACKGROUND

Three traditions have dominated modern research into adjustment to life events.

The first is the literature on stage models of adaptation. These models proliferated after Kubler-Ross (1969) set down five stages for the dying person (denial, anger, bargaining, depression, and acceptance). Stage models generally claim that there are certain cognitive or emotional steps a person has to go through after a life change to regain a sense of equilibrium. There are a number of disadvantages to the stage model approach (which will be described in section 3.3.1), and therefore, this type of research became less fashionable when alternative approaches, such as coping and learned helplessness, were formulated (Wortman and Silver, 1991).

Coping is the process of executing a response to perceived stress (Carver et al., 1989). The coping approach can explain the enormous variety in post life event stress that is observed by postulating different coping mechanisms people use. These are more or less effective for different problems and for different time periods. A weakness of the coping approach is that it may on the one hand postulate mechanisms that people use to deal with events, but it does not describe what it is that people have to deal with in the first place. Furthermore, coping mechanisms are not necessarily related to a particular outcome (Lazarus, 1993; Filip, 1992), whereas, for example, stages of adaptation are. Also, "*measures are not usually formulated to link up with the whole person, who has a particular goal hierarchy and situational intentions, belief systems...coping measures...tend to be disembodied from [the] person.*" (Lazarus, 1993, pp. 242).

In this thesis, the view is taken that coping efforts may help towards good adjustment, and is therefore not directly part of the adjustment process. This idea will be further elaborated in section 3.7.

A third tradition focuses on models of 'learned helplessness'. It is concerned with the lasting effects of being exposed to a situation one cannot control, and in which nothing one does to avoid the situation works. The concept of learned helplessness may not be very useful in this context, because it mainly helps us to explain *why* people have difficulty adjusting to a situation, not *how* people adjust, which is what this chapter is about.

3.3. PERSONAL ADAPTATION TO LOSS

3.3.1. Advantages and Disadvantages of Stage Models of Adaptation

There are a number of advantages to the stage model approach.

The first is that stages are related to particular *outcome* (Heyink, 1993; Livneh and Antonak, 1994). People who have not gone through certain stages successfully will experience distress as a result of the loss, whereas people who have completed these stages will experience a more positive outcome.

Furthermore, they focus attention on the *processes* that lead a person from no adaptation to full adaptation.

Stage models are also very useful in a *descriptive* sense. They describe the full range of emotions that people might experience following loss (Wortman and Silver, 1991) and are therefore often easily recognisable for people in their own experience of grief (Sugarman, 1986).

A number of disadvantages of stage models of adjustment have been identified.
It has been found that people do not always go through stages in the same order, with the same emotions, or with the same intensity of emotions (Wortman and Silver, 1992). For example, Wortman and Silver (1989) have shown that some people indeed seem to go through certain stages, but that others either show no distress at all, directly after the event and in the longer term, or they continue life in a high state of distress for much longer than would be expected. They have also shown that depression (which is present in many stage models of adjustment) is not inevitable or necessary for good adjustment.

A recurring theme is that people do not move in one rigid sequence through stages. Instead, they move back and forth (Clegg, 1988; Sugarman, 1986). The models are therefore difficult to test empirically.
Furthermore, stage models do not explain the potential role that personality, social support, beliefs, norms, and previous experience might play. The *mechanism* of why some people seem to adapt well, and others are devastated therefore remains unclear (Wortman and Silver, 1992; Wortman, Silver, and Kessler, 1993).
And finally, stage models often encompass cognitions, behaviour, and emotions. and therefore generally do not describe recovery at a consistent level of analysis (Clegg, 1988).

The solution for these problems has been to make the concept of stages fuzzier. Stages are not rigidly defined, but have a 'predominant component' (Clegg, 1988) and a 'phasic tendency' (Horowitz, 1979), without concrete boundaries (Shuchter and Zisook, 1993). Phases overlap each other, are fluid, and a person may take "*two steps forward and one step back*" (Sugarman, 1986, p. 143).
In this thesis, the position will be taken that people who have gone though a critical life event face certain '*adaptive tasks*', which, if overcome successfully, should lead to a higher level of well-being than not having 'worked through' these adaptive tasks.

Another solution (which cannot be found in the literature) to the criticism that phases are not sequential would be to formulate phases that are necessarily and logically sequential. This will be further discussed in the next section.

3.3.2. Personal adaptation to loss

Adaptation has been defined from different theoretical positions, using many different concepts, and from different points of view. Different types of adaptation are possible: physical, cognitive, social, or personal. In this chapter and in the whole study, the focus will be on personal adaptation, to the complete exclusion of the former three.

Shontz (1982) pointed out an interesting paradox in the concept of adaptation. From the viewpoint of the person who needs to adapt, there is only a problem as long as he has not adapted to it. When adaptation is successful, the actual problem may still exist, but the interference with his life has disappeared. Adjustment is therefore necessarily related to the outcome of the adjustment process. Heyink (1993) clearly incorporated this notion by linking adaptation to misfortune very closely to the outcome of the process.

"*Adaptation is an intrapsychic process in which past, present, and future situations and circumstances are given such cognitive and emotional meaning that an acceptable level of well-being is achieved*" (Heyink, 1993, p. 1332). In this case the outcome measure is 'well-being', but, obviously, different outcome measures are possible (see chapter four).

Table 3.1. shows the ideas of several different authors of what adaptation constitutes.

Table 3.1 *Different adaptive tasks in the adjustment process according to different authors*

Author(s)	Adaptation process
Bowlby (1973) *Based on:grief following loss*	1) Shock; 2) Searching; 3) Reorganisation; 4) Recovery
Kübler-Ross (1969) *Based on:preparing to die*	1) Denial; 2) Anger; 3) Bargaining 4) Depression; 5) Acceptance
Worden (1982) *Based on: mourning following loss*	1) Acceptance of the new reality 2) Experiencing the pain of grief 3) Adjusting to the new environment 4) Reinvesting energy in new relationships
Parkes and Weiss (1983) *Based on: bereavement*	1) Intellectual recognition; 2) Emotional acceptance; 3) Adoption of new identity
Taylor (1983) *Based on: women with breast cancer*	1) Search for meaning 2) Regain control 3) Enhance self-esteem
Moos and Schaefer (1986) *Based on: life transitions*	1) Establish meaning and personal significance 2) Confront reality 3) Sustain relationships 4) Maintain emotional balance 5) Preserve satisfactory self-image
Janoff-Bullman and Schwartzberg (1991) *Based on: general personal change*	1) Confrontation 2) Resistance 3) Validation 4) Integration
Heyink (1993) *Based on: changes in health*	1) Shifting intra-psychic criteria 2) Cognitive reconstruction 3) Future-time perception
Canine (1996) *Based on: grief following death*	1) Denial 2) Numbness 3) Searching 4) Disorientation 5) Resolution
Parkes (1996) *Based on: reactions to loss*	1) The trauma response 2) The grief response 3) The psychological transitions

People facing critical life events initially seem to go through a period of shock, in which the full impact of what has happened has not dawned on them yet. During this phase, individuals often assume that life can continue the way it was before. An initial diagnosis may have very little impact on somebody who has not been confronted by any lasting changes yet and for whom it is therefore impossible to comprehend the depth of change that is required. However, in their contact with the outside world, individuals are confronted with the fact that their situation is no longer the same as before. This is often accompanied by varying kinds of emotions, such as anxiety, restlessness, anger, and guilt (Parkes, 1996), or feelings of numbness and detachment (Shuchter and Zisook, 1993). These mixed emotions are the result of the confusion over what the likely impact of the event will be and how it will alter the pre-life event equilibrium. The desire not to change this equilibrium may lead the person to *deny* any changes which have occurred. Rather than changing their basic assumptions to fit the facts, people often prefer to change their views of the facts, in order to fit in with their basic assumptions (Janoff-Bulman and Schwartzberg, 1991). Denial is a very common process following death of a loved one (Parkes, 1996; Canine, 1996), the diagnosis of heart problems, stroke, and cancer (Taylor, 1995), or general life changes (Moos and Schaefer, 1986; Janoff- Bulman and Schwartzberg, 1991). Denial is "*a defense mechanism by which people avoid the implications of an illness*" (Taylor, 1995, p. 418). Denial is often seen as a negative process. In the case of traumatic brain injury rehabilitation, denial hampers adjustment because it is blocking a realistic assessment of the situation, it may deter people from seeking help, and it may interfere with rehabilitation efforts. However, more recently the beneficial effects have been stressed as well (e.g. Janoff-Bulman and Timko, 1987). The amount of upheaval a person can face at one time is limited. Denial can protect against upsets which may be too much to bear. It may therefore be, especially in the short term, a beneficial way of coping (Filipp and Klauer, 1991; Lazarus, 1993).

As time goes by, the individual gradually becomes more aware of the difference between his present and pre-life event situation. Largely based upon responses of women who developed breast cancer and their family members, Taylor (1983), Taylor and Brown (1988), and Taylor, Kemeny, Reed, and Aspinwall (1991) suggested that the readjustment process following a personally threatening event focuses around three themes. Firstly, the search for meaning involves the need to understand why a crisis occurred and what its impact has been. It centres around

questions such as: why did the accident/illness happen to me? What are the consequences of what has happened? What is the meaning of my life now?

A second focus is an attempt to regain mastery or control over the event in particular and over one's life more generally. Crucial questions to be resolved are: How can I prevent a similar event from happening again? What can I do to manage it now?

A third theme is the effort to enhance the self and restore self-esteem. Negative events often reduce self-esteem and many intra-psychic mechanisms are used to feel good about oneself again, such as social comparison.

A different approach focuses more on the *process* of how people adjust, rather than on the questions people ask (why did this happen to me?) or on the psychological outcome variables they are trying to regain (control, self-esteem). The main thrust of this line of thinking is that one of the central aspects that critical life events have in common is the fact that it forces a person to give up old perceptions from before the accident and integrate a new reality into his perception of self and the world. This idea has been frequently expressed in the literature. It has been called reorganisation (Bowlby, 1973), acceptance of the new reality (Worden, 1982), emotional acceptance and adoption of a new identity (Parkes and Weis, 1983), integration (Janoff- Bulman and Schwartzberg, 1991), shifting intra-psychic criteria and cognitive reconstruction (Heyink, 1993), resolution (Canine, 1996), or psychological transition (Parkes, 1996).

Parkes (1996) stated that in the case of the loss of a loved one this *creates "a host of discrepancies between our internal world and the world that now exists for us*" (p. 91). This is not confined to bereavement, but also applies to chronic illness. Ideas and assumptions which have become habits of thought and behaviour ('I can walk', 'I can read', 'I am healthy', 'I will work the rest of my life', 'In the future I will be....', etc.), built up over years, are challenged and need to be relinquished. It takes time before a person realises in what ways his/her life has changed and has reorganised his/her basic assumptions in accordance with a new reality. Realisation of the changes and acceptance of the new identity are of central importance in this psycho-social transition (Parkes, 1996).

A very similar process was called 'integration' by Janoff-Bulman and Schwartzberg (1991): *"In the end, a person rebuilds or establishes a new, viable set of basic assumptions*" (p. 495). A sense of continuity is maintained (the 'old' self is not completely discarded) while new

assumptions are integrated. Horowitz (1979) put it like this: "*An ideal adjustment to loss....is to accept it, to replace that which is lost, and to go on living*" (p. 236)

Heyink (1993) argued that reorganisation occurs by shifting expectations and standards against which an event is judged. 'Shifting intra-psychic criteria' refers to the fact that situations and events are always related to intra-psychic criteria and consequently to expectations and aspirations. A low level of expectations can lead to a relatively high subjective well-being (Calman, 1984). Such a shift could come about by comparing one's own situation with that of people who are worse off (downward comparison) or by changing one's criteria and expectations of what is important in life. Furthermore, ideas about the self and the world can be reorganised. 'Cognitive reconstruction' refers to the formation of theories, hypotheses, and explanations of one's situation. It is used to make the present situation acceptable. Processes such as coping, regaining control, wishful thinking, and justification and acceptance of the actual situation are used in order to achieve this.

According to Jacobson (1986), individuals "*typically look backwards.....to their past lives and do not begin to look forward to the reorganisation of their lives until they have given up the idea of what they have lost*" (p.253) during the process of reorganising one's basic assumptions. Parkes (1996) also makes the point that people who are still trying to bridge the gap between the old and the new self typically still look backwards to the past and do not make any plans for the future. Practically, this viewpoint implies that there should be a turning point in time. Before this point, the person still looks backwards to the past to resolve issues from the past, and beyond this point, he has dealt with those issues and they do not occupy the same amount of time any more. This turning point is not likely to be one particular point in time, but it will be part of a gradual process which will be recognised when it has happened. When a new, realistic view of the self and the world has been rebuilt, it is possible to start looking at the future in a realistic way again.

3.3.3. The old and the new self

Many of the theories described above state that when a person has experienced some kind of loss, there is a gap between what the situation used to be like, and a 'new' reality. There are a number of self-theories and cognitive theories in psychology which have investigated extensively what happens when such a gap is perceived.

Working within self-theory, Higgins (1987) introduced the concept of *self-discrepancies*. These are discrepancies between our self concept and how we would ideally like to be or believe others think we should be. She postulated that when people realize that there is a discrepancy between our actual self and their ideal self (e.g. I wish I was more attractive"), they experience dejection-related emotions, such as disappointment, frustration and depression. On the other hand, when people notice a discrepancy between their actual self and what they think they ought to do to meet their responsibilities and obligations (e.g. "I ought to help out my family more financially"), people are vulnerable to agitation-related emotions, such as anxiety and guilt. A number of studies have shown that people with considerable self-discrepancies not only experience negative emotions, but are often indecisive in their behaviour, have unclear self-concepts, and experience loss of self-esteem (Dana, Lalwani and Duval, 1997). Also, in line with Janoff-Bullman and Schwartzberg's (1991) concept that changes to specific, central basic assumptions is more catastrophic than changes to other, it has also been found that the more important these self-discrepant attributes are to the self-concept, the greater are the negative emotions experienced (Higgins, Roney, Crowe, and Hymes, 1994). It would therefore appear that attending to and meeting one's standards is an important function of the self. In relation to head injuries, it is clear that brain injured people may experience a discrepancy between their actual and their ideal self, and are therefore likely to experience dejection-related emotions. These emotions should diminish when such a discrepancy is no longer perceived, i.e. when the person has recognised the changes, has integrated the changes into his new perception of self, allowing him to 'move on'.

Another theory which can inform us about a perceived gap between the new and the old self is a 'consistency theory' originally developed by Festinger (1957): cognitive dissonance theory. The feeling of discomfort caused by information that is inconsistent with our actions or our conception of ourselves as a reasonable and sensible person is called cognitive dissonance (Aaronson, Wilson and Akert, 1997). Cognitive dissonance results when an individual must choose between cognitions and/or behaviours that are contradictory. The person is then motivated to reduce the feeling of discomfort and to avoid dissonance. Festinger (1957) believed that people are actually naturally motivated to reduce or eliminate the dissonance. Like self-discrepancy theory, cognitive dissonance theory also predicts that dissonance will generate psychological distress or feelings of discomfort along with the motivation to reduce the discrepancy. This can happen in a number of ways (Franzoi, 2000):

- Changing attitudes: people can simply change their attitudes to make them consistent with discrepant attitudes or prior behaviour, e.g. "I don't really need to quit, I like smoking".
- Adding cognitions: if two discrepant thoughts cause dissonance, people can add more consonant thoughts, e.g. "Smoking relaxes me and keeps my weight down, which benefits my health".
- Altering the importance of the discrepancy: People can alter the importance of the consonant and discrepant thoughts, e.g. "It's more important to stay relaxed and slim than to worry about maybe getting cancer thirty years from now".
- Reducing perceived choice: People can convince themselves that they are not freely choosing to engage in the discrepant behaviour, e.g. I have no choice but to smoke. I have so much stress in my life now that smoking is one of the only ways to calm my nerves".
- Changing behaviour: People can change their behaviour so it no longer conflicts with their attitudes, e.g. "I'm going to stop smoking again"

This theory is relevant in the context of looking at adjustment following head injury since it is possible that brain injured people experience a state of cognitive dissonance when confronted with the consequences of their head injury. For example:

- Dissonance between their own (new) behaviour and their (old) perceptions of themselves.
- Dissonance between their own (old) perception of themselves and the (new) perception of themselves.

The theory predicts that brain injured people will be motivated to reduce the discrepancy. Classic cognitive dissonance theory predicts that the person will try to reduce the dissonance whilst staying true to (old) behaviour or cognitions. In clinical terms this could be termed 'denial'. This single way of dealing with dissonance is not the only one imaginable, i.e. it is in fact possible to 'give up' old cognitions and behaviour and adopt new ones. This strategy is not corresponds to the last one mentioned in the list above and leads to the giving up of the 'old' behaviour, i.e. smoking. This strategy (of giving up 'old' thoughts or behaviours) is thought to be a crucial aspect of adjustment to loss (see section 3.3.2.).

Cognitive dissonance theory can thus provide a nice explanation of some of the motivational processes underlying adjustment and change following the changes that follow a severe head injury.

3.3.4. Discussion and conclusion

Despite different theoretical positions and different ways of wording it, it would seem from the previous section that certain adaptive tasks are essential for the adjustment process.

Firstly, in order to be able to adjust, individuals will need to recognise the exact implications of what has happened to them. Without knowledge of the changes that have occurred there is nothing to adjust to.

Secondly, individuals will need to bridge the gap that exists between old conceptions of the self and the world, which are no longer correct, and a new concept which has incorporated any changes which have occurred. Acceptance of the loss of part of the 'old' self and acceptance of the 'new' self is a vital element in this process. Without acceptance of the limitations, the person cannot reorganise his assumptions about himself and his abilities and will be preoccupied by the way he was in the past.

Not until reorganisation and acceptance has taken place can the individual start looking forward towards the reorganisation of his life, rather than be pre-occupied by the way s/he was in the past.

This model is different from traditional 'stage' models of adjustment in a number of ways.

Firstly, realisation, acceptance, and looking towards the future have been called 'adaptive tasks', as opposed to 'stages'. Most phase models suggest that people go through these 'phases' as rigid temporal structures (Livneh and Antonak, 1994). It is suggested that the adaptive tasks are not rigid structures, that individuals have to completely finish one task before starting the next. Instead, individuals may accept changes more or less in different periods in their life, or may even revert to denying any changes when that serves a psychological function. The process of adjustment is therefore not irreversible (Livneh and Antonak, 1994).

However, at the same time, these three adaptive tasks (realisation of the limitations; reorganisation/acceptance; and looking towards the future) *necessarily* follow upon each other. This may seem to contradict the previous point, but it does not. Reorganisation and acceptance cannot take place without awareness (if the individual does not realise anything has changed,

there is nothing to adjust to), and looking realistically towards the future cannot take place without reorganisation and acceptance (the individual cannot 'turn the corner' from being preoccupied by his loss to looking realistically towards the future if he has not accepted his loss).

Thirdly, the model does not say anything about the particular type of emotions involved in the adjustment process, or their intensity. It has been shown that grief and depression are not mandatory for transition to the end of the adjustment process (Wortman and Silver, 1989; Livneh and Antonak, 1994).

3.4. THE IMPORTANCE OF 'ACCEPTANCE OF LOSS'

In order to be able to progress from the perception of the way the injured person was before the accident or negative event to a perception of a 'new' self which incorporates the experience, the individual needs to let go of parts of the 'old' self. Practically, this means that the individual will need to accept any losses which s/he may have incurred as a result of the accident. The concept of acceptance of loss is often seen as a central aspect of the adjustment process, but has, surprisingly, not received much scientific attention.

The first major article on acceptance of loss was published in 1956 (Dembo, Leviton, and Wright, 1956; republished 1976) and has influenced research on acceptance of loss until this day. Their research was based on a sample of people with physical injuries, such as amputees. According to the authors, acceptance of loss "*does not mean becoming reconciled to one's unfortunate situation. Instead, acceptance of loss is a process of value change*" (Dembo et al., 1976; p. 51). These value changes encompass four areas:

1. Enlargement of the scope of values

Dembo et al. suggested that a person has started to accept loss when he begins to recognise the importance of other values than those which are presumed lost.

2. Subordination of physique to other values

A focus on physique may lead a person to ignore the importance of other values in life. 'Acceptance' begins when a person's worth is determined by abilities and characteristics which do not revolve around physical abilities.

3. Containment of disability effects

Disability sometimes overreaches its actual effects and can then be seen as globally debilitating. It can then affect other physical abilities, emotional and intellectual spheres, and even the overall value of the person. Containment is the process of separating the actual effects of injury from those abilities and functions that are still normal. The disability is then seen as only one among other aspects of a person.

4. Change from comparative values to asset values

With an asset value, it is possible to focus on the quality of the object, ability, or person being evaluated rather than on its status compared to something or someone else. An example would be that a wheelchair can be valued for its usefulness as means of mobility, rather than devalued as inferior to walking.

Linkowski (1971) developed the Acceptance of Disability Scale, designed on the basis of Dembo et al.'s concept of acceptance of loss. This has been the most widely used measure of acceptance in clinical research. The high inter-relations and factor analysis suggested that the four aspects of acceptance represent a single psychological dimension, a single factor, which he called 'acceptance of loss'.

In clinical research, acceptance of loss is perceived as an outcome measure or as a predictor of outcome, depending on the theoretical stance of the researcher. Hogg, Goldstein, and Leigh (1994) used acceptance of illness as an outcome measure and as a predictor variable in a study (N=59) on the impact of motor neuron disease. It was significantly correlated to the Barthel Index, but not to any of the sub-scales of the Sickness Impact Profile. The authors therefore suggested that "*it is not so much the everyday functional impact....that is significant concerning acceptance of illness but rather the extent of the physical impairments*" (p. 630-631). Furthermore, regression analysis showed that acceptance of illness and coping significantly predicted variance in depression, above the effects predicted by the physical measures. Acceptance of illness and coping therefore seemed to 'buffer' the effects of the severity of illness.

MacCarthy and Brown (1989) found in a study on the psycho-social impact of Parkinson's disease on 136 patients that measures of physical status were the best predictors of acceptance of illness, a similar result to that of Hogg et al. (1994). However, regression analysis did not

suggest the same central role of acceptance of illness in predicting depression and positive well-being as in Hogg et al.'s study. Revenson and Felton (1989) also confirmed the significant relationship between changes in physical limitations and acceptance of disability in a study on adaptation to Rheumatoid Arthritis.

Dodds, Bailey, Pearson, and Yates (1991) developed the Nottingham Adjustment Scale for people with acquired visual impairments. It comprises seven variables thought to play an important role in the adjustment process: general health, acceptance of handicap, self-efficacy, recovery locus of control, self-esteem, attitudes to blindness, and attributional style. They found that *acceptance* is the only variable which is highly significantly correlated with all the other variables, suggesting that "*it may be at the root of the adjustment process*" (p. 309).

Overall, it would seem that 'acceptance of limitations' is a process of value change. A process of modifying a pre-injury perception of oneself to the present reality. 'Acceptance' appears to be highly related to the *direct* consequences of injury (Hogg et al., 1994; MacCarthy and Brown, 1989; Revenson and Felton, 1989) and is often assumed to be at heart of the adjustment process.

3.5. THE DURATION OF ADAPTATION

According to the many stage models of adaptation, people should, on average, adjust more and more over time. If this were true, then a positive relationship should be found between the time post-injury on one hand, and criteria of adjustment on the other hand. However, so far, the available research suggests that there is no clear relationship between time post-injury and adjustment.

In their large study on psycho-social factors in Parkinson's disease (N=136), MacCarthy and Brown (1989) found only slight, insignificant correlations between duration of illness and depression (r=0.03, ns), positive affect (-0.15, ns), and acceptance of illness (0.22, ns). Duration of illness was also not related to feelings of control, particular coping efforts, and social support. Similarly, Hogg, Goldstein, and Leigh (1994) did not find any significant relationship between time since diagnosis and anxiety (-.08, ns), depression (-0.08, ns), acceptance of illness (0.05, ns), or self-esteem (-0.07, ns) in their sample of 59 people with motor neuron disease.

Revenson and Felton (1989) looked at predictors of psychological adjustment in a sample of 45 people with Rheumatoid Arthritis. In a multiple regression analysis (with the variables 'changes in physical limitations', a set of coping strategies, and a previous measurement of the adjustment variables), no significant relationship was found between time since injury and the adjustment measures (mastery; self-esteem; acceptance of illness; negative affect; and positive affect).

Livneh and Antonak (1991), studying a relatively large, mixed group of inpatients and out-patients of a rehabilitation clinic with 30 different types of physical problems (N = 214) found only modest correlations between chronicity of disability and various reactions to trauma, such as anxiety (-0.16, $p < .05$), depression (-0.19, $p < 0.01$), denial (-0.07, ns), shock (-0.21, $p < 0.01$), acknowledgment (-0.05, ns), and adjustment (0.11, $p < 0.05$).

Taken together, these data do not seem to suggest major a major significant relationship between time post-illness and various adjustment variables.

However, further analysis of Livneh and Antonak's data does show some evidence for a temporal development of adjustment. The total group of patients was divided into four smaller groups on the basis of time since injury. Discriminant function analysis showed maximum separation between the two extreme groups, with the two in-between groups occupying intermediate positions. Six factors contributed significantly to the discriminant equation: internalized anger, shock, depression, externalized hostility, acknowledgment, and adjustment. Participants in group 1 (0 to 24 months post-injury) scored significantly higher on shock, anxiety, depression, and internalized anger than did participants in groups 2 (25 to 72 months post-injury) and 3 (73 to 180 months post-injury) who, in turn, scored significantly higher than participants in group 4 (more than 181 months post-injury).

Overall then the picture is unclear. The correlation between measures of adjustment and chronicity of injury appears to be low or modest at best. Dividing the sample up in groups has met with slightly more success.

Krause and Sternberg (1997) showed in a review of cross-sectional studies on the relationship between time since injury and adjustment measures that the results are inconclusive. Their own

study was longitudinal and compared the adjustment of patients with spinal cord injury (N=112) who were more than 2 years post-injury with their level of adjustment 9 years later. Krause found that "*objective aspects of the life situation changed very little*" (p. 654). In contrast "*subjective well-being diminished over the 9-year period*" (p. 655). Patients reported significantly less general satisfaction, more dependency and health problems and poorer adjustment. They also reported more pain, depression and social problems.

3.6. PERSONAL ADJUSTMENT TO TRAUMATIC BRAIN INJURY

The idea that non-neurological factors may be important in the subjective recovery of the patient can be traced back to early articles on the occurrence of psychiatric sequelae following traumatic brain injury (Gordon, 1932; Symonds, 1937; Lishman, 1973). Some people with major impairments seemed to be able to adapt perfectly well to their situation, whereas others, with relatively mild deficits, seemed unable to do so. Hyland (1992) formulated it as follows: "*The relationship between problems and evaluations is....a complex one and it should not be assumed that the presence of problems necessarily means an unhappy life - or that the absence of health problems means a happy life*" (p. 269). In order to be able to explain these kinds of differences between people, non-neurological factors are postulated to play a major role.

As stated before, Teuber (1960) distinguished between the hard and the soft view of recovery following brain damage. The hard view focuses on the effects which are determined by the site, extent, and nature of the lesion. Variation in outcome after brain damage can therefore only be explained in terms of different damage to the brain. The soft view, on the other hand, states that the effects are tempered, if not determined, by the nature of the person who sustains the traumatic brain injury. Factors such as motivation, habits the patient has developed for reacting to failure, education, and premorbid intelligence and plays a role in explaining the variety in outcome. Teuber himself stressed the importance of both 'soft' and 'hard' variables: "*a brain injury strikes a particular person, but this does not detract from the tremendous importance of how and where it strikes*" (p. 322). This is very similar to Symond's (1937) famous remark that "*it is not only the kind of injury that matters but the kind of head*" (p. 1092).

In his book 'The Organism' (1934; 1995), Goldstein adopted the 'organismic' approach. The basis of Goldstein's thinking was his dissatisfaction with the methodology and the results of the

natural sciences. In its place, he formulated a holistic, organismic approach, which comes close to the creation of an 'existentialist neurology' (Sacks, 1995). He talked about the gap between the old and the new self: "*Being well means to be capable of ordered behaviour which may prevail in spite of the impossibility of certain performances which were formerly possible. But the new state of health is not the same as the old one.....Recovery is a newly achieved state of ordered functioning...a new individual norm*" (Goldstein, 1995, p. 334). He was not just interested in symptoms, but also in "*concepts like self-actualization and descriptions of the struggles of patients to come to terms with their new environments...*" (G. Goldstein, 1990, p. 14). These ideas have been picked up by more contemporary psychologists and counsellors who have written about the struggle brain injured people face when trying to come to terms with the consequences of traumatic brain injury, such as Girard and Schadelle (1975), Prigatano, (1991; 1994b; 1995), Miller (1993), and Klonoff and Lage (1991).

Girard and Schadelle (1975) argued that brain-injured people have three cognitive models of themselves, of which they gradually become aware after their accident: Firstly their pre-traumatic body (his 'usual' self),
Secondly, their post-traumatic body with deficits
Thirdly a normally functioning body they think they will have in the future.
Adaptation to the consequences of traumatic brain injury therefore consists of a number of tasks. First, the individual must give up his perception of himself from the past. Subsequently, he must accept his present, changed state.
And finally, he must give up unrealistic dreams about what he can achieve in the future.

Some researchers have used scientific studies to shed more light on the role of 'soft' factors in the recovery of brain-injured people. Which personal or social factors are responsible for variety in outcome has been the particular focus of research.

Research has been done on pre- and post-injury personality and their influence on psycho-social outcome (Malia, Powell, and Torode, 1995), coping strategies (Willer, Allen, Liss, and Zicht, 1991), the relationship between coping strategies and long-term psycho-social outcome (Moore and Stambrook, 1992) and the relationship between social support and outcome (Kozloff, 1987; Leach, Frank, Bouman, and Farmer, 1994). While this is only a selection of the available

studies, the amount of research that has gone into adjustment to the consequences of traumatic brain injury is clearly limited. That is why it is possible that a major text book called 'Recovery after traumatic brain injury' (Uzzell and Stonnington, 1996) contains many chapters on the actual sequelae of traumatic brain injury, but does not even contain one chapter on adjustment to those sequelae. One of the reasons for this anomaly is the fact that the field of outcome following traumatic brain injury does not have a clear theoretical framework within which research can be placed. Research is often driven by practical constraints and personal preferences, without much reference to the possible relationship with a framework or theory. A potential framework for looking at adaptation to the consequences of traumatic brain injury is described in the next section.

3.7. A PERSONAL ADAPTATION MODEL TO TRAUMATIC BRAIN INJURY

3.7.1. Introduction

Clinical studies on the personal and social factors that influence outcome can be put into perspective by placing it into a framework. This also has the advantage that attention can be given to the interrelationship between many of the variables that might play a role (Kendall and Terry, 1996). The following is such a potential framework which describes the personal adaptation process following traumatic brain injury. The framework contains three major components: the adjustment process itself, factors that may enhance or facilitate adjustment, and criteria for or measures of good adjustment.

3.7.2. The Personal Adjustment Process

As outlined in section 3.3.2., the personal adjustment process consists of three adaptive tasks.

The **first** is that the individual with traumatic brain injury becomes aware of and fully realises the actual physical, cognitive, emotional and behavioural consequences of the injury and their impact

on his life. There may be a number of reasons why it is difficult for the brain injured person to do this (Powell, 1995).

Firstly, because people have a tendency to deny painful realities (see section 3.1).

The second is that, especially in the case of severe traumatic brain injury, people spend time in a coma and subsequently in the hospital. In many cases they cannot remember the actual accident because they were in post traumatic amnesia. The change from the pre-injury situation to the post-injury situation is so unexpected and deep, that it takes time to change expectations, hopes, plans, attitudes, and beliefs about the self that have been built up over the years.

The third reason why brain injured people may not be fully aware of the implications of their accident is related to the actual damage to the brain. The frontal lobes are frequently involved in traumatic brain injury (Levin and Kraus, 1994). The frontal lobes are also associated with disturbances in self-awareness (Stuss, 1992; Prigatano, 1991). Self-awareness has been defined as "*the capacity to perceive the self in relatively objective terms [whilst maintaining a sense of subjectivity]*" (Schacter and Prigatano, 1991, p. 13). Fleming, Strong, and Ashton (1996) distinguish three levels of awareness. The first level is awareness of the injury-related deficits themselves. The second level is awareness of the functional implications of the deficits. The third level is an ability to set realistic goals and the ability to predict one's future state accurately.

The **second** element in the adjustment process is the incorporation of any impairments, disabilities, or handicaps into the individual's perception of self. The gap between the 'old' self, who was healthy, to a 'new' self with all its inadequacies needs to be bridged. It can be said that this gap has been bridged when the brain injured person has accepted himself, with all his problems, so that these no longer diminish his perception of himself, but have actually become part of it. In section 3.4., 'acceptance' was defined as a process of value change.

In the only published study which has been carried out on acceptance of disability in the field of traumatic brain injury research, Melamed, Grosswasser, and Stern (1992) found that acceptance of disability was significantly related to work status. Brain injured people (N = 46) who were working had accepted their disabilities more than unemployed people. Acceptance of disability was also significantly related to self-perceived rehabilitation status (Physiological; emotional security; family life; social life; economic self-esteem; vocational self-actualization). The direction of the causation was not investigated. Neither is it clear whether the groups (working versus non-working) differed

in terms of their impairments or disabilities. Silberg (1983; quoted in Melmed et al.,1992) found that acceptance of disability may be severely hampered by lack of awareness of disability.

The **third** element of the adjustment process begins when the brain injured person no longer looks backwards to the way he used to be, but has begun to look forward and to reorganise his life in a realistic manner. Realistic tasks for the future have been formulated and sometimes already started and finished. He should then also experience a normal sense of optimism, just like people who have not experienced a traumatic brain injury (Taylor, 1988).

3.7.3. Factors that may enhance or facilitate adjustment

Factors that may enhance or facilitate adjustment include social support[1], work, coping processes, attributional processes, and personality. Although it is commonly assumed that these variables have a positive influence on outcome, this is not necessarily the case. For example, work can be the source for feelings of achievement and satisfaction (Argyle, 1987), but for brain injured people that is not necessarily the case. Work may confront them with their own inadequacies and thereby set back the adjustment process. Also, certain coping methods may lead to a beneficial outcome, but others may have the opposite effect. For example, problem-focused coping is useful in the case of controllable events, but not in the case of uncontrollable events (Taylor, 1995).

Although the importance of these research into these variables is recognised, they are not the main subject of this thesis.

3.7.4. Measures of / Indicators of / criteria for good adjustment

[1] The researcher strongly feels that social support is very important in terms of the adjustment of severely brain injured people to the consequences of their accident. This was witnessed by the researcher on many occasions at close hand when he interviewed the brain injured person and his carer or partner. It is therefore important that future research should focus on the relationship between social support and adjustment, and on the relative contributions of parents, siblings, partners, and in some cases even children in the adjustment process.

Given the close relationship between the adjustment process and the outcome of this process, it is worth looking closer at how outcome has been measured in clinical outcome studies. This will be done in chapter four.

CHAPTER FOUR Measuring Quality of Life following Traumatic Brain Injury

4.1. INTRODUCTION

The previous two chapters have been concerned with conceptualising traumatic brain injury in a relatively novel manner, as a critical life event to which people need to adjust themselves. The next question is then: how do we judge whether adjustment has been successful? This involves the field of measuring outcome following traumatic brain injury. This will be the concern of this chapter.

'Outcome' is the term that is most commonly used in the traumatic brain injury literature. Other fields use the terms quality of life, need satisfaction, (subjective) health status, health-related outcome, etc. Nearly always, they refer to the same dimensions which are commonly used within traumatic brain injury research. In the remainder of this chapter, both the terms 'quality of life' and 'outcome' will be used.

The chapter is organised as follows.

First an analysis of the difficulties one faces when trying to measure quality of life. Then there is a brief overview of how researchers and clinicians in other fields, in particular the fields of epilepsy research and psychiatry have looked at measuring quality of life. This is followed by a description of the framework within which the consequences of traumatic brain injury are often interpreted, namely the WHO model for interpreting disease and the effects of disease. It is then proposed that this WHO model does not provide an adequate model of quality of life. Additions to the model, especially alternative ways to measure quality of life, are discussed in the final part of the chapter.

4.2. DIFFICULTIES MEASURING QUALITY OF LIFE

There are five immediately obvious difficulties measuring quality of life.

First, there is no absolute definition of quality of life. Everybody agrees that the domains of physical, psychological and social well-being should be included in the definition, but agreement generally stops there. There are large differences between researchers when dimensions within domains are concerned. Quality of life can be defined in terms of symptoms, behaviour, states, feelings, functions, constructs, disabilities and handicaps. There is no shortage of possible constructs to be measured. The main problem is deciding which ones are the most important ones.

Secondly, there is enormous individual variation in quality of life however it is measured. Not only because the great variablity in sequelae of illness or disease, but also because, as Miller (1993, p. 47) put it: "*two individuals with a traumatic brain injury may differ with respect to premorbid IQ, personality, educational level, degree of proficiency in certain verbal or mathematical or artistic skills, socio-economic resources, family and community support systems....., proneness to aggressive outbursts or substance abuse, and so on*". This variation in quality of life and the number of variables which may influence quality of life make it difficult to get a coherent overview of the field.

Thirdly, how should quality of life be assessed? Two obvious ways of assessing individual's quality of life are through unstructured (or semi-structured) interviews or through questionnaires. However, interviews are flexible, can be applied to a broad range of patients, and the risk of missing important information is reduced; on the negative side, they require a lot of time and commitment (Aaronson, 1989) and comparison with other patient groups is made more difficult. Questionnaires are easier to administer and comparison with other groups is made less difficult. On the downside, some of the individual richness that interviews provide is not available (Aaronson, 1989).

Fourthly, there is a process going on over time after critical life event (Schipper, 1990). Aspects of quality of life that are important two months after a traumatic brain injury become less so later on, while other dimensions become more important as time passes. There is a continuous interplay between impairments, the environment and the individual's belief system and thus the way the individual responds to the situation. Any assessment of quality of life - especially of more

subjective aspects of quality of life - is a snapshot, valid for that moment, but the picture may change later.

Fifthly, whose view of quality of life should be measured? Quality of life can be assessed by the clinician, by the patient, or by someone who is close to the patient (Aaronson, 1989; Jackson, Hopewell, Glass, Warburg, Dewey, and Ghadiali, 1992). Clinicians have generally not known the person prior to the injury and therefore cannot determine absolute change in a person's functioning (Jackson et al., 1992). Furthermore, clinicians (and significant others as well) cannot be fully aware of the individual's personal and social problems, because they lack the insider's perspective. Significant others may also be biased towards portraying the brain injured person in a more positive or negative way, depending on their own feelings and attitudes towards that person. However, the patient's self-reports may not be definitive because of possible cognitive problems and/or possible lack of insight. Some aspects of a person's functioning are logically inaccessible to the brain injured person, such as degree of insight or judgmental abilities (Jackson et al., 1992).

4.3. OUTCOME/QUALITY OF LIFE MEASURES IN OTHER FIELDS

The development in quality of life research in a number of other fields will be discussed below. The field of 'epilepsy' was chosen because it is a neurological disorder, just like traumatic brain injury, and outcome research appears to have developed along the same lines as outcome research into traumatic brain injury. The field of psychiatry was chosen because a lot of research has been done on the status of chronic psychiatric patients. The similarity with traumatic brain injury is obviously the chronicity of the condition. The final section (4.3.3) will look at more generic measures of quality of life.

4.3.1. In Epilepsy

In much epilepsy research, it is recognised that there is more to outcome than purely medical outcome. 'Quality of life is the ultimate outcome' (Devinsky and Cramer, 1993). 'Our goal should be a happy, productive and healthy life for the patient' (Devinsky and Penry, 1993). The psychological

effects that recurrent seizures might have on an individual partly resemble those after traumatic brain injury. People with seizures may have cognitive impairments following their fit(s). They may have difficulty returning to work, or are not allowed to. Also, they may lose their independence because they cannot live alone, cannot drive a car, need to adapt their everyday lifestyle and become dependent on other people in some areas of their life. A result of all this is often a considerable drop in self-confidence and self-esteem (Devinsky and Penry, 1993). The main difference with people who have sustained a traumatic brain injury is that most seizures can be controlled with medication. It is an episodic disorder, rather than a state (Cramer, 1993). People with epilepsy therefore do not necessarily have to break radically with the past and also, they do not necessarily look forward to a non-productive future. Furthermore, patients with head injuries often experience a profound personality change that interferes with their social life. This is usually not the case in epilepsy.

Research into outcome in epilepsy has followed roughly the same path as outcome research after traumatic brain injury.

First, attention was given to medical aspects of outcome, such as seizure severity and side effects of medication (Devinsky, 1993). There has been a long discussion on how to evaluate seizure severity (Cramer, 1993), similar to the discussion in the traumatic brain injury literature on how to rate traumatic brain injury severity.

Later, the main focus of research shifted to (measures of) psycho-social aspects of epilepsy (Dodrill et al., 1980; Jacoby, 1992; Vickrey, 1993).

Vickrey (1993) described the Epilepsy Surgery Inventory (ESI). It has a generic core of dimensions that enables comparison with other patient groups. The SF-36 Health Survey was chosen for this purpose. Supplementing these core dimensions is a group of epilepsy specific dimensions. These consist of cognitive function, role limitations due to memory problems, health perceptions and overall quality of life.

A Development Group of the American Epilepsy Society has been working on a new measure, the QOLIE (Quality of Life in Epilepsy) (Devinsky and Cramer, 1993; Perrine, 1993). The QOLIE also has a generic core consisting of the SF-36 Health Survey. Epilepsy-specific items have been added in the areas of seizure-specific health perceptions, seizure worry, attention and concentration, memory, language, working and driving limitations, medication effects, overall quality of life, social support and social isolation.

4.3.2. In Psychiatry

Within psychiatry, the principal focus of quality of life assessment has been more on conditions such as schizophrenia, chronic depression, bipolar disorder, and severe personality disorder (Lehman and Burns, 1990). It is often acknowledged that a description of symptoms does not suffice as a measure of quality of life (Baker and Intagliate, 1982; Simmons, 1994; Endicott, Nee, Harrison, and Blumenthal, 1993). Evaluation of quality of life usually takes place across a wide range of domains, first of all because mental disorders affect many areas in the patient's life and secondly because these effects often do not subside once the acute symptoms have gone. Quality of life and clinical symptoms are both part of an interactive model (Lehman and Burns, 1990). Much emphasis has been placed on interpersonal interaction, social and role functioning and psychological well-being. Functional outcome is commonly measured in terms of housing, finances, dependence, leisure and employment - the same dimensions that are commonly used in the evaluation of functional outcome after traumatic brain injury. Most measures in use in psychiatry can therefore be said to contain a mixture of objective and subjective dimensions. Much less emphasis has been placed on physical outcome and activities of daily living.

Psychiatric patients often suffer from disturbances in consciousness, emotion, thinking, speech and memory (Kaplan and Sadock, 1988). Psychopathology affects the patient's rating of his quality of life (Lehman and Burns, 1990). The reliability of self-report measures of outcome in psychiatric patients can therefore be doubted in much the same way as self-reports after traumatic brain injury are clouded by cognitive deficits and by disturbances in awareness. Lehman and Burns (1990) therefore suggest that an assessment of quality of life should always be accompanied by a concomitant assessment of psycho-pathologic symptoms to reduce the confounding effects of psychiatric symptoms.

4.4. THE WORLD HEALTH ORGANIZATION MODEL[1]

The WHO (1980) put forward a framework in which to interpret disease and the effects of disease. A distinction was made between pathology, impairments, disability, and handicap. Pathology refers to the underlying damage or abnormal processes within an organ or organ system. An impairment is the direct *"loss or abnormality of psychological, physiological, or anatomical structure or function"*, associated with symptoms and signs. They lead to disabilities, the "*restriction, or lack of ability to perform an activity within the range considered normal for a human being*". They are often associated with functional capacities. Handicap represents "*the socialisation of an impairment or disability, and as such it reflects the consequences for the individual -cultural, social, economic, and environmental - that stem from the presence of impairment and disability*". An example of the WHO model in action in the case of traumatic brain injury would be the following: brain damage (the pathology) results in poor planning and organisational capacity (the impairment) leading to a reduced ability to organise one's personal life (the disability) and the loss of a job (the handicap).

The rationale behind the WHO model (pathology results in impairments, which lead to disabilities, which lead to handicaps) has been challenged (Johnston, 1996) but it is still widely used and is very useful as a descriptive framework.

4.5. IS THE WHO MODEL SUFFICIENT AS A MODEL OF QUALITY OF LIFE?

What is good or satisfactory quality of life? This topic is very rarely discussed in the literature. However, implicit in all quality of life measures is the suggestion that certain outcomes are better than others. On the one hand, one can take a purely medical stance and only consider medical outcome as the important criterion for good outcome. This is what Filipp and Klauer (1991) call a 'homeostatic' model of functioning. The purpose is to return the patient to a pre-injury level of functioning. It can be illustrated by considering the case of a broken leg. When the broken leg has

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[1] Since the ideas in this thesis were first conceived, the terminology of the WHO model has changed model has changed to **"The International Classification of Functioning, disability and health"**

healed, the person will usually resume everything he was doing before the accident. Goldstein (1934; 1995) formulated this position as follows: " *if regaining health consisted of bringing about a sufficient removal of the deviations of the individual's norm that had been caused by the disease, then health could be regained only by a complete restitution of the former normal state* (*restitutio ad integrum*)" (p. 330). However, the model is not useful in the case of illnesses and injuries that have long-lasting, persistent consequences, such as spinal cord injury or traumatic brain injury. As pointed out in section 1.5., sequelae of traumatic brain injury are persistent and cause long-lasting upheaval of the individual's personal and social life, at least up to 15 years after the accident (Thomsen, 1984; Witol et al., 1996).

A variant of the homeostatic model is to return the patient to the highest possible level of functioning from a medical perspective. The underlying assumption is that the less pathology and the fewer impairments a person has, the fewer disabilities and handicaps he will experience. This is the basis of the WHO model (Johnston, 1996) and it is also the basis of many approaches to the rehabilitation of people who have sustained a traumatic brain injury (Brooks, 1991). However, this model can be challenged as inadequate on several grounds.

Firstly, it can be argued that in many cases, the goal of rehabilitation of the brain injured patient should go beyond the medical perspective and the WHO model and should take the patient's own perception of his outcome into account.

Second, there is not a necessary relationship between pathology and impairments on the one hand and quality of life on the other hand. As Goldstein (1934; 1995) put it: "*There are undoubtedly people who do not consider themselves sick, although a defect may remain*" (p. 330). There may be (non- neurological) mediating variables that significantly influence quality of life.

Thirdly, what is considered to be a disability or handicap by a clinician, may not necessarily be perceived as such by the patient. Disability and handicap are relative terms.

And the fourth challenge is that illness may also have positive effects, besides the negative consequences.

These four points will be discussed in sections 4.6, 4.7, 4.8 and 4.9, respectively.

4.6. SUBJECTIVE QUALITY OF LIFE

4.6.1. Objective versus Subjective Traumatic Brain Injury Outcome Measures

The use of questionnaires has been very popular in evaluating the neuro-behavioural and psycho-social effects of traumatic brain injury. Some, for example the Ways of Coping Questionnaire (e.g. Moore and Stambrook, 1992), the General Health Questionnaire (e.g. Livingston et al., 1985), and the Functional Independence Measure (FIM; e.g. Hall et al., 1993), were originally designed for other samples. Forer (1985) reviewed 18 different measures of functional status which have been used in traumatic brain injury samples and found that only one of them had been specifically designed to measure the impact of traumatic brain injury. Other measures had been modified for use in brain injured samples, such as the Sickness Impact Profile (Temkin et al., 1988; Temkin et al., 1989; Smith, 1992) and the Katz Adjustment Scale (Fabiano and Goran, 1992; Jackson et al., 1992). Since 1985, some questionnaires have been specifically designed to measure the effects of traumatic brain injury. Table 4.1. lists a number of these measures.

Table 4.1. A selection of questionnaires which have been used to evaluate outcome following Traumatic Brain Injury

Scale	***Authors/used by in HI population***
Glasgow Outcome Scale	Jennett and Bond, 1975; Jennett, 1984;
Neuropsychology Behavior and Affect Profile	Nelson et al., 1989; Nelson et al., 1993;
The Neurobehavioral Rating Scale	Levin et al., 1987;
Neurobehavioral Functioning Inventory	Kreutzer et al., 1996;
Agitated Behavior Scale	Corrigan, 1989; Corrigan and Bogner, 1994;
Brooks' Personality Scale	Brooks et al., 1983; 1987;
Glasgow Assessment Schedule	Livingston and Livingston, 1985;
Disability Rating Scale	Rappaport et al., 1982; Gouvier et al., 1987;
Portland Adaptability Inventory	Lezak, 1987; O'Brien and Lezak, 1988;
The Community Integration Questionnaire	Willer et al., 1994;
The Community Outcome Scale	Stillwell et al., 1999
Functional Independence Measure +	
Functional assessment measure	Hall et al., 1993
Barthel Index	Mahoney and Barthel (1965)
Revised Barthel	Novak et al., 1996
The Wessex traumatic brain injury matrix scale	Shiel et al. 1999
Overt aggression scale	Yudofsky et al, 1986
Katx Adjustment Scale	Katz and Lyerly, 1963
Mayo-Portland Adaptability Inventory	Malec and Thompson, 1994
Brain Injury Community Rehabilitation Outcome Scales	Powell, 1999
Community Integration Questionnaire	Willer et al, 1993
Sickness Impact Profile	Bergner et al., 1981

Ideas about how to evaluate outcome have shifted over the years. In the last two decades, studies in the field of traumatic brain injury have tried to assess outcome and the effectiveness of rehabilitation programs not so much in physical or cognitive terms, but much more in terms of

real life outcome (Brooks, 1991). This change reflects concerns about how people are managing outside the hospital, in the community. It is also an attempt to measure the effectiveness of rehabilitation clinicians to provide 'real life' services that are relevant to people who have suffered a traumatic brain injury. The most widely used variable has been return to work (Brooks et al., 1987b; Ben-Yishay et al., 1987; Vogenthaler et al., 1989; Ezrachi et al., 1991; Christensen et al., 1992; Ryan et al., 1992; Ruff et al., 1993; Dikmen et al., 1993; Prigatano et al., 1994c).

A number of comments can be made about these studies and the questionnaires they have used. First, most studies reflected the influence of the medical model (Crisp, 1993). They have mainly focused on symptoms, deficits, impairments, functional loss, and psychiatric syndromes. What has not been looked at so much is how brain injured people adjust to these impairments, disabilities, and handicaps (see Chapter 3) and how it has affected their perception of themselves and the world. No attention has been given to the 'person as a whole', e.g. how the person is functioning in relation to the world. This includes any problems the person may have, but it also includes aspects of a person's functioning that *are* going well.

Second, their results have not always yielded information that could be applied to many social (non-clinical) situations (Crisp, 1993). Knowledge of the way a person has changed in terms of impairments, disabilities, and handicaps may not be relevant in the context of the brain injured person's personal life (see also next section). For example, when a brain injured person no longer makes much recovery, it is virtually impossible to improve his functioning in terms of impairments or disabilities any further. A concept that has been used in the psychiatric literature is 'Comfort rather than cure'. Baker and Intagliate (1982) stated: "*Some conditions are just not susceptible to 'cure' and the best one can hope for with present knowledge is to comfort the suffering. In the case of psychiatric patients, it is now generally recognized that it is unrealistic to expect high levels of rehabilitation for the majority of these clients and most will not return to competitive employment or attain a high level of social functioning*" (p. 69). The same case can be made about people with a severe traumatic brain injury. As has been demonstrated, traumatic brain injury patients face long-term physical, cognitive, emotional, behavioural, and social problems which do not decrease in magnitude over the years (see Chapter 1). Expectations therefore need to be scaled down and in the long term, the focus should be on the subjective

quality of living, rather than on the quality and quantity of impairments, disabilities, and handicaps. Figure 4.1 shows this change over time from seeing a traumatic brain injury simply as a neurological event, towards viewing it as a critical life event. Assessment and rehabilitation efforts in the early days are mainly focused on restoring the patient's capacities so that they are as close as possible to the way they were before the accident. Once further recovery can no longer reasonably be expected, it becomes more important to facilitate adjustment to enhance the subjective recovery.

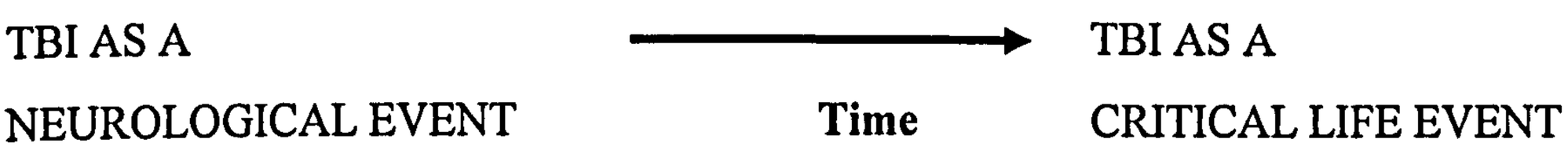

Figure 4.1. Over time, traumatic brain injury changes from a neurological event into a critical life event

Most studies into the effects of traumatic brain injury have looked at outcome as a set of objective factors or constructs which are assumed to be important for the patient. There are, however, two traditions of measuring quality of life (e.g. Baker and Intagliate, 1982; Anderson, 1988; Baker et al., 1992; Simmons, 1994; Fletcher, Gore, Jones, Fitzpatrick, Spiegelthaler, and Cox, 1992). Quality of Life has an *objective* component, which is usually concerned with disabilities and handicaps, as defined in the WHO model. It also has a *subjective* component, which includes concepts such as 'psychological well-being' and 'happiness'.

A distinction is sometimes made between two types of objective indicators of quality of life. The first refers to activities or domains which can be investigated without the subject's help. This includes symptoms and impairments, but also situational factors such as income, housing, education, and employment. The second objective indicator does involve reports from the subject himself. The WHOQOL group (1993) distinguish between 'perceived objective' and 'self-report subjective'. The first is "*a person's global evaluations of their behaviour states or capacities*" (p. 154), and the latter is defined as "*perceived satisfaction/dissatisfaction with behavior, state or capacity*" (p. 154). Most of the quality of life measurements in the traumatic brain injury literature have been of the 'perceived objective' type and it seems that subjective approaches, in which the patient is allowed to evaluate his own life, have been neglected in

evaluating the effects of traumatic brain injury. Other fields, however, have not neglected subjective approaches , for example the fields of mental illness (Baker and Intagliate, 1982; Endicott, Nee, Harrison, and Blumenthal, 1993), cancer research (Baker, Curbow, and Wingard, 1992), stroke research (Anderson, 1988; Viitanen, Fugl-Meyer, Bernspång, and Fugl-Meyer, 1988), spinal cord injury (Schulz and Decker, 1985; Fuhrer, Rintala, Hart, Clearman, and Young, 1992) and illness in general (Beaufait, Nelson, Landgraf, Hays, Kirk, Wasson, and Keller, 1992; Ruta and Garratt, 1994). Not only is it sensible to look at the subjective recovery from a clinical point of view. It has also been advocated from a policy point of view. A relatively recent report on the care for people with acquired brain injury (HAS, 1997) also called for a long-term care approach that takes the views of the affected person into account: "*...a pathway of care that lasts from diagnosis to death (or full recovery in some instances of acquired brain damage) and ensures that the needs of the individual and their carers are catered for at each stage*" (p. 113-114).

4.6.2. Subjective quality of life

There is a wealth of literature on people's subjective evaluations of life, both in the normal population and in populations with a particular conditions. The general headings are often 'subjective well-being', 'happiness', 'subjective health status', or 'satisfaction'. Many reviews have appeared of the field (e.g. Diener, 1984; 1993; Diener, Suh, Lucas, and Smith, 1999; Kahneman and Diener, 1999; Argyle, 1987) and on the causes of well-being (e.g. Argyle and Martin, 1991; Headey and Wearing, 1989, 1992; Ryff and Keyes, 1995). People experience a high or a low subjective well-being because they continually appraise events, life circumstances, and themselves in terms of goodness-badness (Diener, 1993).

Subjective well-being can be broken down into a number of different components (Argyle, 1987; Diener, 1993; Diener et al., 1999).

The first component is a cognitive assessment of the general state one's life is in, called 'satisfaction'.

The second component is an ongoing affective judgement, sometimes called 'pleasantness' (Diener, 1993) or 'elation/joy' (Argyle, 1987). It consists of the emotional side of happiness and is subject to more fluctuation than satisfaction.

The third component is the absence of any psychological distress (Argyle, 1987).

Research has found that life satisfaction and affective well-being tend to fall together on a common well-being factor when a second-order factor analysis is performed (Diener, 1993).

It has been found that positive well-being is not simply the opposite of depression or negative well-being (Bradburn, 1969; Diener and Emmons, 1985). Positive and negative well-being are only modestly correlated, a finding which has been confirmed in a number of studies, using different methodologies (Diener, 1984). Also, there are different factors which predict positive and negative well-being (Argyle, 1987). The implication of this is that subjective well-being can be studied in its own right without reference to depression.

Several methods for measuring subjective quality of life are available, including experience sampling, qualitative descriptions of people's lives, recording people's memories for good and bad events, questionnaires, and physiological measures. This multitude of tests reflects the fact that subjective quality of life is not a unitary concept, but has multiple facets, that must be assessed through global judgements, momentary mood reports, physiology, memory, and emotional expression (Diener et al., 1999).

Measures of satisfaction have been used more often as markers of subjective quality of life than measures of affect. This could be because of the following three reasons (Pavot and Diener, 1993).
First, people may ignore negative emotional reactions while still recognising the undesirable factors in their lives.
Second, affective responses tend to be immediate and of short duration, whereas satisfaction ratings seem to reflect more a long-term perspective.
And finally, affective responses may reflect unconscious motives and bodily states to a greater extent, as opposed to more conscious values and goals (Pavot and Diener, 1993).

4.6.3. Subjective well-being after illness

It has often been found that people have an amazing ability to adapt to/recover from negative events in terms of their subjective well-being (Taylor, 1983; Diener, 1984; Filipp and Klauer, 1992; Heyink, 1993; Diener et al., 1999). A few examples:

- Schulz and Decker (1985) found that people with spinal cord injury who were 20 years post-injury only reported a slightly lower (not significant) subjective well-being than that of a healthy control sample, despite major disablement.
- Brickman, Coates, and Janoff-Bulman (1978) compared lottery winners, accident victims (paraplegic and quadraplegic) and a group of controls one year after the event. Lottery winners were in general not happier than the controls, nor were the accident victim unhappier than the controls. There was, however, a significant difference between the lottery winners and the accident victims.
- Wortman and Silver (1992) reported that in the first week after spinal cord injury, victims are psychologically distressed, but three weeks after the accident, they already report more happiness than depression, anxiety, or anger. This effect did not appear to be caused by denial. A similar result was found in a study on how parents cope with the loss of a child.
- It has often been found that the well-being of cancer patients differs little from that of healthy controls in the long-term (VanderZee, Buunk, DeRuiter, Tempelaar, VanSonderen, and Sanderman, 1996).
- Blind people are generally not unhappier than normal, healthy people (Cameron, 1972; in Brickman et al., 1978);

However, it is generally assumed that although a person who experiences an irrevocable loss will go through a period of intense distress, this will not last indefinitely. In fact, after a relatively brief period of time, the person is expected to achieve a state of recovery and return to normal functioning. But there is also evidence that indicates that people do not necessarily adapt completely and rapidly to all circumstances (Diener et al., 1999). For example,

- Lehman, Davis, Delongis, Wortman, Bluck, Mandel, and Ellard (1993) found that bereaved spouses and parents who were 4-7 years after the sudden loss of a family member reported significantly more psychological symptoms and less well-being than a matched control group.
- Parkes and Weiss (1983) interviewed widows and widowers and showed that more than 40% of their sample still experienced moderate to severe anxiety even 2-4 years after the event.
- Lehman, Wortman and Williams (1987) focused explicitly on the long-term effects of the sudden, unexpected loss of a spouse or child 4 to 7 years earlier. Interviews wetre conducted with bereaved respondents who were matched with a control group of non-bereaved respondents on sex, age, income, education and number and ages of children. Significant

differences between bereaved and control respondents were found on several indicators of functioning, including depression and other psychiatric symptoms, social functioning, divorce, psychological wellbeing and mortality.

- In a cross-sectional study of patients who were physically disabled up to 38 years earlier, Shadish, Hickman, and Arrick (1981) reported that many of them still thought about the things they could not do since their injury and 'really missed' these things almost weekly.
- Krause (1997) studies a group of 235 adults with spinal cord injury in a longitudinal study. They were followed up after 1 year and subsequently 9 years later. Between 1 and 9 years several indicators of subjective outcome declined, including aspects of their social life, sex life, family relationships, emotional adjustment, lack of control, making friends, and depression.

Taken together, the evidence suggests that prevailing notions of recovery deserve reconsideration. There is evidence that a substantial minority of individuals continue to exhibit distress for a much longer period of time than would be commonly assumed.

Many different theories have been proposed to explain differences in happiness. It is often thought that adjustment processes (see chapter three) mediate between the impact of chronic illness and subjective well-being (a hypothesis which will be tested in this study in Chapter nine). Furthermore, judgement or adaptation level theories of happiness, as defined and proposed by Diener (1984) are often thought to play a role in the recovery from chronic illness. These theories state that subjective well being is the result of a comparison between a standard and the reality. The standard can be either internal or external. Habituation and contrast effects are responsible for gradual adaptation to positive or negative life events. These two psychological processes will be discussed in the rest of this section.

Physiological evidence for habituation has been found in animal and human studies (Taylor, 1995). When exposed to a moderate chronic stressor, rats show an initial increase of markers of physiological stress (corticosteroids), followed by a return to normal levels. The same results have been found in humans. However, full return to pre-stressor levels does not seem to occur for the immune system following exposure to long-term stressful events.

Habituation effects have also been looked at in the context of social cognition. When an event occurs, it is evaluated and the result of this evaluation will determine whether the event has a

positive or a negative effect. This is called the 'endowment' effect of events (Tversky and Griffin, 1991). It is the immediate emotion that it elicits in terms of goodness or badness (Diener, 1984). Over time, the same event no longer elicits the emotions as strongly as directly afterwards, until they fail to evoke them at all. This is called the 'habituation effect'. People will adapt to good events, so that they no longer evoke happiness, and to bad events so that they will no longer evoke unhappiness. The individual will gradually return to a particular standard, which is based on that person's own experience: he will continually adapt to the overall level of events (Brickman et al., 1978; Diener, 1984; Argyle and Martin, 1991). Frederick and Loewenstein (1999) stated that "*hedonic adaptation refers to a reduction in the affective intensity of favorable and unfavorable circumstances*" Diener (1984) claimed a similar point: "*An individual's standard will eventually move up or down to any level or circumstance; it is only departures from this level that can produce affect*" (p. 567).

The second way in which adaptation occurs is through contrast effects. The individual will compare his present situation to an internal standard, usually particular experiences or a particular period in the past. Initially, a very positive event may make a person very happy (the endowment effect), but this same positive event may render subsequent, similar experiences less exciting. Similarly, negative life events may produce unhappiness in the short term, but they also make subsequent, similar experiences less harmful or distressing (Tversky and Griffin, 1991). For example, when a person goes to the theatre in The West End and sees a wonderful play, then that experience will make seeing a similar play in the village hall seem less exciting and enjoyable. On a larger scale, it has been found that people who remembered the most poverty during the great depression in the thirties in the United States even appeared slightly more contented than people who remembered less or no poverty (Elder, 1974).

Contrast effects can work in two different ways in the case of traumatic brain injury.

First, the person can view his accident as something very negative in the past which makes present negative events seem only minor. These events would then not make the person as unhappy as they would have done before the accident because the amount of suffering the person has gone through in the past has become the standard against which future events are judged.

Since this experience was very intense and strong, negative events that happen to him now will seem only minor.

Secondly, the person may also look at his pre-injury past in which he still had all his abilities and compare it to a less fortunate present. Happy events in the present would then not evoke such an emotion, because they are compared to a glorious past. The standard against which current events are judged is then a very positive one in the past. Current events cannot 'beat' a glorious past and the result will be a low level of subjective quality of life. Brickman et al. (1978) found that paraplegics "*exhibited a strong nostalgia affect, rating their past as much happier than did controls*" (p. 924). Similar feelings were reported by Shadish, Arrick, and Hickman (1981) in a group of spinal cord injury patients, even up to 38 years post-injury. Schulz and Decker (1985) found that even a group of 100 people with spinal cord injury who were on average 20 years post-injury rated their life before the injury as happier than their present life. And finally, Keen (1995) reported that 38 % of a group of 200 brain injured people replied 'definitely applies to me' to the question: do you often think about the way you were before your accident?

Tversky and Griffin (1991) stated that in order to maximise happiness, "*one should find ways to treat the positive experiences of the past as different from the present (to avoid comparison with the glorious past). By the same token, one should compare present conditions to worse situations in the past (to enjoy the benefits of a positive contrast)*" (p. 103). Therefore, depending on the strategy brain injured patients use, they should experience a higher or a lower subjective quality of life.

4.6.4. Social comparison as a mediator between health problems and subjective outcome evaluations

The previous section described internal comparison processes a brain injured person may be employing. This section will discuss the use of social comparison as a mediator between health problems and subjective outcome evaluations. Festinger (1954) originally described social comparison theory. It stated that people have a need to evaluate their opinions and abilities, to figure out their strengths and weaknesses, in order to have an accurate view of themselves. Festinger (1954) stated that you compare yourself with other people when there is no objective

standard to compare yourself against and when you experience some uncertainty about yourself in a particular area. Research has shown that people do not generally compare themselves to anyone (Gilbert, Giesler, and morris, 1995). Instead, people usually compare themselves to others who are similar to them on the important attribute or dimension. People can compare themselves to others in two different directions. In the case of *upward social comparison*, people compare themselves to individuals who are better than they are on a particular trait or ability, in order to determine the standard of excellence (Aaronson, Wilson and Akert, 1997). In contrast, in the case of *downward comparison*, people compare themselves to individuals who are worse than they are on a particular trait or ability. It is assumed that this latter strategy is a self-protective, self-enhancing strategy (e.g. Aspinwall and Taylor, 1993): if you compare yourself to people who are not as good as you are, you will feel better about yourself. Exline and Lobel (1997) found that people with low self-esteem particularly use and benefit from the use of downward comparison.

Social comparison theory has also been applied to health problems. It has been suggested that in stressful situations individuals try to compare themselves to others who are worse off (Wills, 1981). This would suggest that people with serious health problems also compare themselves to people who are worse off. This has indeed been found to be the case. E.g. Stanton, Danoff-Burg, Cameron, Snider, and Kirk (1999) found that women with breast cancer frequently engage in downward social comparison. Affleck and Tennen (1991) found similar results in a sample of patients with arthritis. Other studies have looked at the effects of social comparison on subjective outcome. These studies have generally found that people who engage in downward comparison experience less psychological distress than those who do not (e.g. Affleck et al., 1987; VanderZee et al, 1998).

It is therefore likely that social comparisons are also taking place in people with moderate to severe head injuries. In the case of upward comparison, it would seem unlikely that brain injured people compare themselves to other brain injured people who are better off than they are. Instead, it is likely that they will compare themselves to people who have not had a head injury instead. One would expect that brain injured people who do engage in upward comparison see themselves as worse off than people who have not had a head injury, and this is likely to have a negative effect on their evaluation of their subjective adjustment and outcome.

In the case of downward comparison, brain injured people may experience a sense of relief that at least they are not as badly off as another brain injured person, and this is likely to have a positive effect on their evaluation of their subjective adjustment and outcome.

4.7. THE RELATIONSHIP BETWEEN OBJECTIVE AND SUBJECTIVE QUALITY OF LIFE

4.7.1. Introduction

The distinction between objective and subjective quality of life leads to the question of the relationship between the two.

In the normal population, this question has been looked at in a number of different ways. Generally, the finding has been that objective factors, defined as 'resources', only have a very weak relationship with subjective well-being (Diener, 1993). These 'resources' include variables such as health, income, education, and physical attractiveness. People who work are, however, generally considerably happier than people who are unemployed. On the whole, it seems that the relationship between these objective factors and subjective well-being is lower than the relationship between more personal factors and subjective well-being (Argyle, 1987, Diener, 1993). Personality (extroversion and neuroticism), self-esteem, maturity, and success in achieving goals are all highly correlated with subjective well-being.

4.7.2. The Relationship between Health Status and Subjective Well-being

The relationship between objective factors and subjective well-being has also been looked at in populations with a (chronic) illness. Objective factors are then defined as medical symptoms, disabilities, and self-perceived medical condition ('perceived objective' health status).

At the level of medical symptoms and impairments, no relationship has generally been found with subjective well-being.

In a study on the long-term effects of spinal cord injury (N=140), Fuhrer, Rintala, Hart, Clearman, and Young (1992) did not find a statistically significant correlation between their motor index score (a reflection of the extent of paralysis) and the life satisfaction index (LSI). It must be stressed, however, that the LSI is not a pure measure of satisfaction, but also includes questions related to self-esteem and acceptance. Similarly, Crisp (1992) showed in a study on the long-term consequences of spinal cord injury (N=60) that there was no relationship between severity of injury and a measure of satisfaction. Unfortunately again, this measure was not a pure measure of life satisfaction either, but included the dimensions zest for life, optimistic mood tone, and congruence between desired and achieved goals. Finally, in a study investigating the psycho-social factors in Parkinson's disease (N=136), MacCarthy and Brown (1989) found a small (0.20), yet insignificant relationship between the severity of impairments and Bradburn's Positive Affect Scale.

At the level of functional disabilities, the picture is less clear. Fuhrer et al. (1992) reported no relationship ($p = 0.07$) between the Functional Independence Measure and the Life Satisfaction Index. MacCarthy and Brown (1989) found a moderate relationship ($r = 0.26$) between activities of daily living and positive affect. Viitanen, Fugl-Meyer, Bernspäng, and Fugl-Meyer (1988) showed, in a study on life satisfaction in long-term survivors after stroke (N=62), that activities of daily living were significantly related to changes in pre- and post-stroke measures of life satisfaction ($r = .26$ and $r = .29$).

Handicap is mostly moderately and usually statistically significantly related to subjective well-being. The three dimensions of the Craig Handicap Assessment and Reporting Technique (CHART), namely mobility ($r = .21$), social integration ($r = .26$), and occupational status ($r = .24$) were all significantly correlated to the Life Satisfaction Index in Fuhrer et al.'s study in SCI patients. Crisp (1992) also found that employment status was related to positive affect after SCI ($r = 29$). Social integration was also significantly related to global life satisfaction after stroke (Viitanen et al., 1988).

Self-perceived health status is often significantly related to subjective well-being. This is the case for perceived general health status (Fuhrer et al., 1992; Crisp, 1992; Schulz and Decker, 1985) and for more disease specific health status. Fuhrer et al. (1992) found a significant correlation between self-perceived general health status and the Life satisfaction Index ($r = .41$) in their sample of

people with spinal cord injury. Schulz and Decker (1985) found in a study on the long-term adjustment to physical disability in SCI patients (N = 100) that their own perception of their disability status was significantly related to the Life Satisfaction Index (r = 0.40).

One study in the traumatic brain injury literature has looked at the correlates of quality of life. Webb, Wrigley, Yoels, and Fine (1995) used an outcome measure which included the Life Satisfaction Index, 'independence', standard of living, and activity participation. They telephoned 116 people who were on average two years post-injury to assess their present status. Quality of life was highly related to employment status (r = 0.52) and what they call 'impairments', which include variables such as pain, confusion, weakness and health problems. The Functional Independence Measure (r = 0.38), the number of different types of rehabilitation (r = 0.18), self-blame (r = 0.22), and ethnicity (r = 0.20) were also significantly related to outcome.

4.7.3. Conclusion

It appears that the further one progresses from impairments, to disabilities, to handicaps, to self-perceived health, the greater the relationship with subjective quality of life. The severity of the injuries do not seem to be a major determinant of subjective quality of life, but the social consequences of the injuries and the way the person interprets his own health status seem to be more important. Whether such differences in association between these WHO variables on the one hand and subjective well-being exist statistically has not been looked at, but will be one of the major focuses of Chapter Eight.

The logical conclusion of this point is that it is possible that a clinician's opinion of somebody's situation (in terms of impairments and symptoms) does not necessarily coincide with that of the carers of the patient or the patient himself, in terms of their perception of their situation. For example, Davies and Mehan (1988) have shown that, while the speech of an 18 year old girl who had sustained a severe traumatic brain injury was incomprehensible to two neurologists, a speech therapist, an occupational therapist and two medical sociologists, it made much greater sense to her parents. So while a clinical assessment in a clinical setting clearly showed a severe speech deficit, this did not pose a very significant problem in the context of the patient's home environment and therefore did not necessarily affect her subjective quality of life.

To summarise, it can be said that there does not seem to be a necessary relationship between, on the one hand, the extent of the individual's medical symptoms and impairments and, on the other hand his own subjective evaluation of his situation. This will be explored further in the brain injured sample in Chapter eight.

4.8. THE RELATIVITY OF QUALITY OF LIFE

Research into outcome after a traumatic brain injury is nearly always carried out from what Stoker, Dunbar and Beaumont (1992) have called a 'monothetic' point of view. In this universalistic approach, "*the assumption is made that a single and common set of dimensions, scales or factors is equally applicable to all individuals with regard to their quality of life*" (Stoker et al., 1992). However, a description of the subject's status for example, in terms of mobility, independence, return to work, cognitive deficits, anxiety and even depression, ignores the *relative* importance that each variable might have for each individual. A simple hypothetical example of this fact. Man A is a painter; he is not a very talkative person. Man B is a politician; he relies heavily on speaking in terms of his career and his social status. Both men suffer a stroke in the speech areas of the brain, without any other accompanying impairments. Man B is devastated, man A is almost unaffected. The subjective quality of life of man B diminished more than that of man A because the subjective value they give to the same consequences of the same neurological event differs sharply. Crisp (1993) has formulated it as follows: "*much of the previous literature has not acknowledged that living with a disability carries a variety of meanings, and occurs in different situations, for different individuals*" (p. 394).

The brain injured person's values as to what is important in his life or not, are rarely taken into account when measuring outcome. Any sequelae of a traumatic brain injury go through a personal and societal 'filter'. It is through this filter that the subjective quality of life of the subject is determined. The consequences of the traumatic brain injury are judged and weighed *against the individual's expectations* and the result of this process -the person's subjective quality of life- is highly personal and subjective (Calman, 1984). The WHOQOL group (1993) also include ratings of perceived importance of a particular domain in their quality of life measure. The study of what values are important to an individual therefore deserves serious investigation.

4.9. PERSONAL GROWTH FOLLOWING ILLNESS

4.9.1. Introduction

A severe traumatic brain injury leads to long-term consequences to which the person needs to adapt (see chapter one). This process of adaptation is not necessarily a wholly negative process. In fields other than traumatic brain injury the idea has been proposed that illness may not only have negative effects, but that it may also have consequences which the person suffering the illness interprets as positive or good (e.g. Moos, 1982; Moos and Schaefer, 1986; Hyland, 1992). Changes in behaviour, values, priorities, and social relationships, which were forced upon the person by the illness, may not necessarily be perceived as negative. Adjustment to critical life events has even been equated to growth (Filipp and Klauer, 1992). The next section will describe some of the positive effects of illness which have been reported in the literature. In the reported studies, participants compared their present situation to their pre-injury situation and *perceived* positive changes.

4.9.2. Positive Effects of Illness

Smith (1979) reported that 66% of the medical-surgical patients she interviewed spoke of changes in values and priorities. A shift from emphasis on work to enjoying family life more was typical. Seventy percent of the interviewees felt differently toward other people, with a greater concern for others and a sense of community with others. The motivation given for these changes was often that they realised the fact that they had a limited life span and felt they had hit rock bottom.

White and Liddon (1972) found that survivors of cardiac arrest often report a "*transcendental redirection*" in their life. This often consisted of a religious conversion or a philosophical readjustment. They often spoke of the need to 'finish unfinished business' and had a desire to give up old ways which they felt were wrong.

In the field of bereavement, Miles and Crandall (1986) argued that most attention has focused on the negative consequences of bereavement and that the potentially positive consequences have

been ignored. In three different studies on reactions of parents to the death of their child, they found positive responses. These would, in some cases, even outnumber the negative responses. They identified a number of typical positive statements, including being more compassionate and caring of others, having a stronger faith, realising the importance of spending more time with the family, learning to prioritise and reorganise goals, and being aware of the preciousness and fragility of life which helped them live each day more fully.

Bennett (1987) claimed that a minor traumatic brain injury not only has negative effects, but can also have positive effects. Many of his patients said that a minor traumatic brain injury was not the worst thing that ever happened to them. He believed that personal growth can be described in psychological or in spiritual terms. Spiritual growth involves redefining one's relationship with the universe or purpose in the universe. The patient may reassess his personal values, goals, and life direction. It may be a time to ask the question: "*what do I want from my life*?". Because friends have often abandoned the individual, he may appreciate his remaining friendships more than he used to. Generally, having been through the recovery of a minor traumatic brain injury often leaves the patient with a greater appreciation of life and of the fragility of life, according to Bennett (1987).

Shelley Taylor and her group (Taylor, Kemeny, Geoffrey, and Aspinwall, 1991; Taylor, Collins, Skokan, and Aspinwall, 1989; Collins, Taylor, and Skokan, 1990) have looked at positive illusions and life changes in life perspective following threatening events. They found that over 90% of cancer patients reported positive changes in their lives as a result of the cancer experience. They reported beneficial effects such as an increased ability to appreciate each day, the willingness to put more effort into relationships, and feelings that, as individuals, they were stronger, more self-assured, and more compassionate.

In many studies, positive changes have only been a report of what patients have said. In the following study, reporting positive changes was also related to outcome to investigate any possible beneficial effects.

In an excellent study of bereaved spouses and parents who had lost a loved one in a motor vehicle accident 4-7 years earlier, Lehman, Davis, Delongis, Wortman, Bluck, Mandel, and Ellard (1993) compared groups of bereaved respondents reporting various positive life changes

to non-bereaved matched controls. Respondents reported significantly more positive then negative life changes. Seventy four percent of respondents reported at least one positive life change. They also found that while the number of negative life changes was significantly related to happiness, the number of positive life changes was not. When positive changes were sub-divided into positive changes in terms of self-perception, social relations, and life orientation, it was only positive changes in terms of social relations that was associated with happiness. When compared to the control group, the bereaved sample reported significantly more psychopathological symptoms and less happiness.

Overall, it was concluded that "*reports of positive life changes were unrelated to levels of psychological symptoms and well-being*" (Lehman et al., 1993, p. 106).

4.9.3. Discussion

Shontz (1982) pointed out that clinicians tend not to look beyond the symptoms and the problems that a patient presents, and therefore tend to miss what positive effects may result. The above review of the literature makes it clear that traumatic events can in many cases also have positive consequences. There appear to be a number of causes of this positive reinterpretation of oneself, others, and life in general.

Firstly, the facts that the person (or someone close) has come close to death and may therefore have become more aware of his own fragility and mortality. This in turn leads to the realisation that 'life is short' and that one needs to live it to the fullest.

Secondly, because the person is faced with loss, he will usually have to change priorities and plans. This reorientation can subsequently lead to new plans and a new purpose. For example, a person who can no longer work may change his priorities from work to family.

These new plans will only be reported as a 'positive life change' by the brain injured person when they are *perceived* as positive.

Thirdly, 'positive reappraisal' is an effective coping mechanism that is often adopted by people after trauma. It has been defined as "*construing a stressful transaction in positive terms*" (Carver, Weintraub, and Scheier, 1989, p. 269). It has been found to be related to good outcome in a population of severely brain injured patients (Moore and Stambrook, 1992).

By focusing on the possible positive consequences, the intention is not to minimise the negative consequences and the distress caused by traumatic brain injury.

However, many studies have reported that people do perceive positive effects coming out of very negative events. Lehman et al. (1993) found that reporting positive consequences in terms of social relationships was related to a more positive outcome. Reporting positive effects should therefore be looked at as an adaptive method that deserves serious investigation.

4.10. CONCLUSION

The literature on the consequences of traumatic brain injury has often been looked at from one perspective: the clinician's. Much is known about the sequelae of traumatic brain injury in terms of the WHO model: impairments, disabilities, and handicaps. What has been overlooked is the fact that these may not play a major role in the life of the brain injured patient himself. Other fields (such as epilepsy and psychiatry) have evolved in terms of outcome research from symptom focused to patient focused outcome research. Not much is known about how the *brain injured person* perceives his own situation, and whether that perception is related to his actual clinical situation. Most of the descriptions of the effects of traumatic brain injury have been of the 'perceived objective' type. Subjective self-reports have been largely ignored. In the current study, quality of life will therefore be defined more broadly: in terms of people's prioritisations of their needs and how well these are satisfied, rather than in strictly medical terms. It is clear from research on other chronic illnesses that people have an amazing ability to recover their subjective quality of life, and can, in many cases, even draw valuable lessons from the experience. The fact that not much research has gone into this area is a large omission, which will partly be rectified by this research project.

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CHAPTER FIVE Research Questions, Methodology, and Participants

5.1. INTRODUCTION

The previous chapters have stressed the persistent effects of a severe traumatic brain injury, the need to adjust to the consequences, a number of adaptive tasks (including becoming aware of the changes, accepting them, and stop looking backwards towards the past) and the need for outcome research which takes the person's own perceptions into account.

This chapter will be concerned with the research questions which flow from this review of the literature, the research methodology of the study, and a description of the brain injured and the control population used in this study.

5.2. RESEARCH QUESTIONS AND HYPOTHESES

This thesis is concerned with two major questions.

Firstly, what is the subjective quality of life of a sample of severely brain injured people (Chapter seven).

Secondly, can subjective quality of life be predicted? The prediction of subjective quality of life will particularly focus on the strength of prediction of injury-related variables versus the strength of prediction of adjustment-related variables (Chapters eight, nine, and ten).

In addition to these two main questions, this study will also focus on a number of other possible predictor variables of subjective quality of life (reported positive effects, state of the insurance claim, and time post-injury), and variables that can be perceived of as markers of adjustment (suicide attempts) (Chapter eleven).

The questions addressed in this study were:

A. Subjective Quality of Life following Traumatic Brain Injury

1. What is the subjective quality of life of a sample of severely brain injured people who are more than one year post-injury?

2. How does the subjective quality of life and other measures of adjustment of a sample of severely brain injured people compare with the subjective quality of life of a matched, healthy control group?

The research conducted in this area has been mixed (see section 4.6.3.), different studies have shown a variety of different levels of subjective quality of life in different studies of participants who have chronic medical conditions or have suffered loss (of a close family member). It was therefore felt that it was not reasonable to have a specific hypothesis, but to make this an exploratory study instead.

B. Predicting Subjective Quality of Life

This section will particularly focus on the strength of prediction of subjective quality of life of injury-related variables versus adjustment-related variables.

3. The relationship between subjective quality of life and objective, injury-related variables. The specific questions addressed were:
   What is the relationship between the subjective quality of life of a sample of severely brain injured people and:
   a) A measure of the severity of the traumatic brain injury (post traumatic amnesia)?
   b) Neuro-behavioural problems reported by a carer?
   c) Self-reported neuro-behavioural problems

It was expected (on the basis of the findings reported in section 4.7.) that:

d) through the progression from severity of the traumatic brain injury, to carer-perceived neurobehavioural problems, to patient-perceived neurobehavioural problems, the relationship with subjective quality of life becomes stronger.

4. What is the relationship between the subjective quality of life of a sample of severely brain injured people, and non-neurological factors, in particular the extent to which they have mastered the three adaptive tasks described in section 3.7.? The specific questions addressed were:

What is the relationship between the subjective quality of life of a sample of severely brain injured people and

a) Their level of awareness of their limitations as a result of the traumatic brain injury?
b) Their level of acceptance of limitations?
c) Their past - present - future orientation? (i.e. whether the person is still looking towards the past or has begun to look towards the future)

It was expected that people who have more awareness, have accepted their limitations, and who look towards the future will have a higher quality of life than people who do not do so. This hypothesis is based on the literature described in section 3.3. in which stages of adaptation are related to outcome. In particular, Heyink (1993) hypothesised that there is a link between advancing in terms of stages of adaptation and improved outcome.

A further hypothesis concerned brain injured people's past future orientation. Contrast theories of happiness (section 4.6.3.) predict the following three outcomes:

4c-I Brain injured people who look towards the past will have a lower subjective quality of life than brain injured participants who look towards the future, given the fact that they have a pre-injury past which may be perceived of as 'more glorious', whereas the controls do not necessarily have such a 'glorious past'

4c-II Brain injured people who often compare their present situation to that before the accident, will be less well adjusted than brain injured people who do not make such comparisons.

4c-III Brain injured people who compare their present situation to their situation directly after the accident, will be better adjusted than brain injured people who do not make such comparisons.

These hypotheses were formulated on the basis of the contrast theories described in section 4.6.3.

It is important to stress that the relevant variables ('looking towards the past', 'past-present comparisons') are concerned with the brain injured person's *perception* of the past, rather than what actually happened. There may in fact be a gap between what the person was really like before the accident and what he currently *thinks* he was like. As such, there may be retrospective recall bias. This gap is not the subject of this research. It is argued in this thesis that what the brain injured person *thinks* he was like is more important than 'true' recall.

4d- I) Brain injured people who compare their own situation to that of other people who have not had a head injury are engaging in upward social comparison. Their subjective quality of life is therefore likely to be lower than that of brain injured people who do not engage in such comparison.

4d-II) Brain injured people who compare their own situation to that of other brain injured people who are worse off than they are, are engaging in downward social comparison. Their subjective quality of life is therefore likely to be higher than that of brain injured people who do not engage in such comparison.

C. Other aspects of the subjective Recovery following severe Traumatic brain injury

5. What is the relationship between the subjective quality of life of a sample of severely brain injured people and time post-injury?

The literature on adjustment to and outcome following illness and loss has not shown a clear relationship between time post-injury and outcome (see section 3.5.) It was expected that there will be no relationship between time post-injury in the present brain injured sample and subjective quality of life and adjustment.

6. a. Do severely brain injured people or their significant others retrospectively report suicide attempts following their accident?

b. Is it possible to predict suicide attempts from injury-related data?

c. Do people who have attempted to commit suicide have a lower subjective quality of life or are they less well-adjusted than people who have not attempted to commit suicide?

With regard suicide and suicide attempts, no specific hypotheses were formulated, because at the time when this study was designed, the researcher was not familiar with any studies on suicide which had been published in the literature. This aspect of the research was therefore completely exploratory.

7. a. Do severely brain injured people and their carers report positive effects of their accident?

b. If so, what is the nature of such reported effects?

c. What is the relationship between reported positive consequences on the one hand, and level of adjustment and subjective well-being on the other hand?

It was expected that, in line with the findings of Lehman et al. (1993), brain injured people will report some positive effects of the traumatic brain injury, but that those who do report positive (or 'learning') effects do not have a higher subjective quality of life than brain injured people who do not report such effects.

5.3. DESIGN OF THE STUDY

This study has a cross-sectional design using a two-pronged approach: a qualitative and a quantitative study. The qualitative data were used to clarify information obtained in the quantitative study and they were also quantified and used for statistical analysis.

Ethics approval was obtained from the NAPREC (Nursing and Allied professions Ethics Committee) on 13.11.1995. The ethics committee approval letter can be found in appendix 5.1., along with a participant information sheet and a consent form.

5.4. METHODOLOGY

5.4.1. Introduction

Silverman (1993) distinguished between two different schools of social science: positivism and interpretative social science. Positivism is sometimes called the 'etic' or the 'third person' perspective. This approach is associated with objective, analytic, clinical or research stances toward human behaviour and "*is external to the situation under analysis*" (Goode, 1983, p. 239). This is the traditional and most commonly used approach in the clinical assessment of brain injured patients. The clinician has an external criterion against which the patient's behaviour is evaluated. This external criterion can take the form of :

(a) A theory, in the sense that behaviour is evaluated in the light of existing ideas of what a certain behavioural pattern represents.

(b) It can take the form of norms, in that the patient's performance is compared with a matched control group.

(c) And it can take the form of the clinician's experience; the clinician has seen patients with similar stories and similar behaviour and assesses the patient in the light of these experiences.

Practically, this approach often leads to fault finding (Goode, 1983) or a focus on disability rather than ability. In a (neuro) psychological examination, the patient is often assessed in many areas, including memory, intellectual abilities, speed of information processing, attention, anxiety, depression, etc. The clinician starts delving deeper into one area, once any evidence of an impairment has been found, to understand its exact nature. The (neuro) psychological profile that is thus obtained is then often used to extrapolate performance and social or personal consequences of the traumatic brain injury to the outside world. It is also used to guide rehabilitative efforts, like cognitive rehabilitation. Within the neuropsychological literature, many questionnaires used also seem to reflect the 'third person perspective' because they mainly enquire after the patient's own health status, and therefore fall into the 'perceived objective' category.

There are a number of practical advantages to quantitative (including questionnaire studies and psychometric assessment) approaches.

Firstly, it is possible to use established measures with satisfactory reliability and validity.

Secondly, it is possible to generate substantial amounts of data with only a few questionnaires or tests.

Thirdly, interaction with the patient is kept to a minimum. It is therefore less likely that the presence of the examiner will influence the answers given by the subject.

Interpretive social science is sometimes called the 'emic' or first person perspective. The first person perspective aims to study behaviour "*in its natural state, undisturbed by the a priori assumptions or hypotheses of the researcher*" (Davies, 1995). This viewpoint is discovered from within the situation under study (Goode, 1983). Many different versions or definitions of qualitative research have been put forward (Silverman, 1993) and a number of advantages of this approach over quantitative analysis have been identified.

Firstly, it is more flexible than quantitative research. Questions to the subject can be tailored to the personal circumstances.

Secondly, there is a focus on the meaning of variables within a social context, rather than a focus on numerical data. There is a preference for 'natural settings' as the primary source of data. And understanding about what it is like to have had a traumatic brain injury can be obtained by encouraging people to describe their world in their own terms (Rubin and Rubin, 1995).

5.4.2. The Relationship between Qualitative and Quantitative Analysis

It is obvious that first and third person perspectives are not mutually exclusive. For example, in almost any neuropsychological assessment, the clinician will listen to the patient's side of the story *and* evaluate his performance/behaviour against an external criterion. However, clinicians generally put far more emphasis on testing patients from the third person perspective, mainly because this gives them 'hard' evidence of any malfunctioning in the patient's performance. Also, there is no standardised way of looking at the first person perspective. Besides the third person perspective, this project will focus on the first person perspective, for a number of reasons.

Firstly, the first person perspective can be used to target help where the patient needs it most. An analysis of the first person perspective will inevitably produce practical, real life information that is relevant to the patient's personal and social needs. The first person perspective may therefore have implications for the treatment of brain injured people.

Secondly, a clear understanding of the first person perspective provides insight for the professionals involved and so it may modify, or should modify their own ideas of what constitutes appropriate input towards good outcome.

Keith (1994) described five possible relationships between qualitative and quantitative data. Two of those (which will be used in the current study) are:

- Qualitative data can be transformed into quantitative units for statistical analysis. This is especially useful when sensitive topics are explored (such as suicide) which are difficult to explore in questionnaires.
- Qualitative data can be used as the key to deciphering the meanings of quantitative data. For example, if the correlation between two variables is not as high as expected, then qualitative data can shed light on the specific situation of 'outliers' to explain the lack of relationship between the variables.

The next two sections (5.4.3. and 5.4.4.) will focus respectively on the qualitative and quantitative procedures used in this study.

5.4.3. Qualitative Procedure

5.4.2.1. CONCEPTUAL BACKGROUND AND STRUCTURE OF INTERVIEWS

There are different types of qualitative methodology (Silverman, 1993). The most well known is Grounded Theory (Glaser and Strauss, 1967). Researchers slowly and steadily build up a picture from qualitative interviews to form explanations and theories that are 'grounded' in the details and examples of the interviews. Grounded Theory is often used in situations when the researcher wants to build up a picture of a particular situation from 'nothing'. The researcher enters the situation without any preconceived ideas and then slowly builds up a picture of it. However, in many cases the researcher *does* have preconceived ideas and is only interested in the answers to particular questions, as is the case in the current study. The questions in the qualitative interview and the subsequent analysis of the answers can then be restricted to those that are relevant to the research

hypotheses. In the case of *content analysis*, the specific answers given are coded into specific categories (Silverman, 1993) which can then be analysed further.

Silverman (1993) discussed to what extent interview data reflect a true account of the world the interviewee inhabits. According to the pure 'externalist' position, interviews can be treated as reports on external realities. The pure 'internalist' position, however, claims that interview data "*express interpretive procedures or conversational practices present in what both interviewer and interviewee are doing through their talk and non-verbal actions*" (Silverman, 1993; p. 107). The former seems to treat interview data as 'true' and the latter treats it as 'not necessarily true', but instead a product of the interaction between interviewer and interviewee. Silverman argued that the dichotomy between 'true' and 'false' is a misleading polarity. Whyte (1980) claimed that ambivalence is a 'fairly common position of man' and that one may hold different opinions at different times. It is therefore impossible to try to discover the 'true' attitude or sentiment of the interviewee. Silverman (1993) therefore suggested that interview responses are not simply true or false *reports* of reality, but instead, these responses can be treated as *displays* of perspectives and moral forms. By analysing interview responses, one gains access to a 'cultural universe' and its content of moral assumptions. Interviews therefore not necessarily provide 'the truth', but instead provide access to how people account for their troubles and good fortune.

In qualitative interviews, there is variation in the degree to which the interviewer directs the interviewee (Rubin and Rubin, 1995). Interviews can have a completely unstructured, a semi-structured, or a completely structured format. In the case of the first, the interviewer introduces a topic, but has few questions in mind. In the case of the second, the interviewer wants specific information and guides the discussion by asking specific questions. Completely structured interviews only give the interviewee the chance to answer specific questions. In the present study, a semi-structured interviewing format was chosen. The interview consisted of main questions, which were prepared beforehand, probes (when responses to the main questions lacked sufficient detail, depth, or clarity), and follow-up questions, to pursue the implications of answers to the main questions. The structure of the interview is a guide (Kaufman, 1994). The investigator refers to it to make sure that all the topics have been covered. The exact wording, the order of questions, and probes are unique in each interview and depend on the informant and the nature of the response (Kaufman, 1994).

The semi-structured interview for brain injured people and their carers in the current study contained a section on demographic and biographical data, which included questions pertaining to the participants' age, marital status, pre-existing head injuries, physical or mental problems, and their educational and occupational history.

Interviews with brain injured people and their carers were guided by the stages of interviewing set out by Rubin and Rubin (1995). These are:

1. Creating a natural environment.
2. Encouraging conversational competence.
3. Showing understanding.
4. Getting facts and basic descriptions.
5. Asking difficult questions.
6. Toning down the emotional level.
7. Closing while maintaining contact.

The objective during the interview was to initiate "*a dialogue with a real person and engage the interviewee as a human being, not as a study object*" (Kaufman, 1994, p. 123).

The assessment of brain injured patients and their carers usually takes place in hospital surroundings, with which the brain injured person is unfamiliar. They may not feel completely at ease there and may therefore exhibit typical behaviours of 'the way one generally behaves in a hospital' (Sarafino, 1990). If the patient is observed in familiar surroundings, it would help create a 'natural environment' (Rubin and Rubin, 1995) in which the brain injured person and his carers would feel free to be more at ease in their own home. Their behaviour may therefore be more natural and more like the way they usually behave. According to Silverman (1993), all qualitative research fundamentally depends on observing people in their own territory. All the interviews with brain injured people and their carers therefore took place in their own home.

5.4.2.2. PROCEDURE OF THE QUALITATIVE INTERVIEWS

A semi-structured interview was designed which contained the main questions and prompts (see appendix 5.1.). The interview was subsequently practised and piloted on a small group of brain

injured people (patients 01-03). These interviews were *not* analysed and coded as they were part of the pilot.

All interviews were tape-recorded, and subsequently transcribed by a third person (not the researcher) who was a professional secretary.

5.4.2.3. CATEGORIES FOR THE QUALITATIVE STUDY

Responses given by the brain injured person and his significant other were placed into categories so that they could be used for statistical analysis. The reliability of this process will be described in the 'results' section in Chapter nine. Below, the categories into which responses were placed will be described. The variables that were coded were, respectively, awareness of limitations, acceptance of limitations, past-future orientation, suicide, and positive effects of the traumatic brain injury.

Awareness of limitations.

'Awareness of limitations' was measured in two ways.

Firstly, by subtracting the patient's own perception of his neurobehavioural status from his significant other's perception.

Secondly from a clinical impression of 'awareness of limitations'. The categories used were borrowed from 'the awareness interview' by Fleming et al. (1996). They distinguished between self-awareness of injury-related deficits, i.e. the physical, cognitive, social, and emotional consequences of the accident and self-awareness of the functional consequences, i.e. the sequelae in terms of independent living, work, leisure, driving, and other everyday activities. On the basis of qualitative interviews with brain injured people, Fleming et al. (1996) designed a coding system that contained four levels of awareness in the three categories described above (see also appendix 5.2.). Patients were placed into certain categories on the basis of the following instructions to the rater:

(a) Comparison of the deficits the brain injured person mentions and the deficits the significant other mentions

(b) Direct question to the significant other: "*does the brain injured person have full insight/awareness*?"

(c) General clinical impression

Section 9.2.1. will describe exactly how reliability was established.

Acceptance of limitations was defined by Ben-Yishay (1988; 1996) as part of a progress report of his 'therapeutic milieu' rehabilitation programme. Acceptance involves 'learning to live with his or her new life' according to Ben-Yishay (1996) and consists of four tasks:

a) Calm resignation to the reality that the injury has changed one's life in many respects and that it has imposed certain restrictions on what one may achieve in the future
b) The conviction that life, as is, plus the future (realistic) options that remain available, can be tolerated with a "*calm dignity*", without undue agitation, and without feeling that one has been totally "*vanquished*" by life and turned into a "*has been*".
c) The ability to derive from one's present life some satisfactions, (which make one's life "*worthwhile*", and help healing one's shattered sense of "*self*", in spite of the fact that one's present and probably future ability to achieve has become diminished compared with the pre injury status).
d) An improvement in one's self-esteem.

The fourth criterium was dropped in the current study, since self-esteem was viewed as a result of acceptance, and therefore separate from it. Moreover, the study also contained a questionnaire which specifically measured self-esteem.

Acceptance was coded from three different points of view: the brain injured person's, the carer's, and a neutral observer's.

'Acceptance of limitations' was coded into three different levels:

1. Full acceptance
2. Some acceptance
3. No acceptance.

The categories were kept to a maximum of three to increase the reliability and the clarity of the study.

Section 9.3.2. will describe exactly how reliability was established.

Past - future orientation.

A number of categories were concerned with the brain injured person's past - future orientation. They included the following (between brackets is the person to whom the question was addressed):

a) Would life have been different if he had not had the accident (brain injured person)?

b) Does he think about what might have been (brain injured person and significant other)?

c) Has there been a 'break' with the past? Has there been a moment at which the patient felt that he was no longer thinking about the accident and its consequences as much as he did before, but instead started thinking more about what lies ahead of him? (brain injured person and significant other)

d) Does the brain injured patient often compare his abilities now to those he had before the accident? (brain injured person and significant other)

e) Does the brain injured person often compare his abilities now to those directly after the accident? (brain injured person and significant other)

Questions a and b were coded into simple yes and no categories. Questions d and e also included the category 'sometimes' between 'yes' and 'no'.

Questions c was categorised into

1) Is definitely still preoccupied with the past
2) Lives only in the here and now, from day to day, and
3) Is forward looking, plans for the future.

Section 9.4.2. will describe exactly how reliability was established.

Suicide attempt and suicidal thoughts are difficult to measure retrospectively in a brain injured population, since the brain injured person may not remember whether or not he has thought about it, or even whether he attempted to do commit suicide. His judgement may therefore not be completely reliable.

The alternative, to ask the carer, may also not yield reliable results, since the brain injured person may not always have talked to him or her about his suicidal thoughts or suicide attempts.

The third alternative is therefore to combine the records of both the brain injured person and his carer and to score 'suicide' as the highest category given by either. The four labels for 'suicide' were:

1. Has never considered it
2. Has thought about it, but never seriously
3. Has seriously considered suicide but has never attempted it
4. Has attempted suicide

Positive consequences from traumatic brain injury was looked at in two ways.

First, both the brain injured person and his carer were asked whether they feel that anything positive has come out of the fact that the person had a traumatic brain injury. The answers given were coded into simple 'yes' and 'no' categories.

Subsequently, the patient was asked in what sense he felt that the accident had had positive consequences. The answers given were coded into categories taken from Lehman et al. (1993):

1. Self-perception: Feelings of strength or increased sense of self as a result of loss; ("*My traumatic brain injury has helped me learn about myself*"; "*Because of my traumatic brain injury, I know that I have a lot of will power/determination*"; "*I feel proud that I have been through all this and that I am still here*")
2. Social relations; Increased concern for others; increased emphasis on the family: ("*My traumatic brain injury has shown me the value of close friends*"; "*My traumatic brain injury has shown me the value of a close family*")
3. Life orientation; Greater appreciation for life; increased religiosity/faith; focus on enjoying the present; increased acceptance of reality; ("*My traumatic brain injury has helped me value my life more now*"; "*I am better off now after my traumatic brain injury, because I was destroying myself before*")

Furthermore, during the interview, the brain injured person and his carer were asked a number of open-ended questions about his life, such as "*are you (is he) happy with your life*" and "*what are you (is he) happy/unhappy about*?" in order to gain more insight into the general and more specific subjective state of the brain injured person.

5.4.4. Quantitative Procedure

5.4.4.1. INTRODUCTION

The quantitative study consisted of questionnaires filled in by both the brain injured person and his carer. Table 5.1. shows the specific questionnaires given. Copies of all the questionnaires are in appendix 5.4.

Table 5.1. Questionnaires given to the brain injured person and to the carer

Brain injured person	Carer
Barthel Index	
Nottingham Adjustment Scale - Self-esteem	
Life Priority Index	
Future Expectations Scale	
Hospital Anxiety and Depression Scale	
Acceptance of Illness Scale	
Satisfaction with Life Scale	
Life Satisfaction Questionnaire	Life Satisfaction Questionnaire
Neurobehavioral Functioning Inventory	Neurobehavioral Functioning Inventory
Brooks' Personality Questionnaire	Brooks' Personality Questionnaire

5.4.4.2. PROCEDURE

Most brain injured people and their carers filled in the questionnaires when the researcher visited them. If it was not possible to finish the questionnaires in time, they were given a pre-paid envelope to return them to the researcher. Five patients and their carers filled in questionnaires without being interviewed. It was stressed that they should try to fill in the questionnaires separately, without helping each other. They then sent them back in pre-paid envelopes.

The Barthel Index was filled in by the researcher on the basis of information given by the significant other. However, More than 80% of all clients scored maximum points on the Barthel Index. It was therefore decided not to use it in any statistical analyses.

5.4.4.3. THE QUESTIONNAIRES

Brooks Personality Questionnaire

The Brooks Personality Questionnaire was included in order to get a quantitative measure of 'awareness of limitations'. The exact procedure will be described in section 9.2.1.

The Brooks Personality Questionnaire was designed by Dr Neil Brooks and has been used in several studies he has conducted with colleagues (Brooks and McKinlay, 1983; Brooks et al., 1986a; Brooks et al., 1987a; Brooks et al., 1987b). The scale was specifically designed for use with brain injured patients and consists of 18 bipolar adjectives (for example, talkative-quiet; even tempered-quick tempered; rely on others-do things for themselves) which either the relative fills in about the patient or the patient about himself.

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) is a short, reliable valid and much used measure of anxiety and depression. It consists of 14 questions. Seven relate to anxiety, the other seven to depression.

The HADS has a number of characteristics which make it particularly attractive to use (Zigmond and Snaith, 1983; Wilkinson and Barczak, 1988):

- It is relatively unaffected by any concurrent physical illness
- It is phrased in a way that makes it non-threatening to clients
- It was designed for repeat administration so you can measure outcomes for the progress of interventions
- It has been used in hospital, outpatient, and community settings
- It has been extensively researched in terms of its validity and reliability and is often used by psychiatrists, clinical (neuro) psychologists, and doctors.

The Neurobehavioral Functioning Inventory

The Neurobehavioral Functioning Inventory (Kreutzer, Marwitz, Seel, and Devany Serio, 1996) was developed because of dissatisfaction with existing measures. Existing measures, such as the Neurobehavioral Rating Scale, have not been subjected to rigorous psychometric evaluation. There is especially concern that "*behavior, skills, and symptoms measured in a structured clinical setting do not necessarily correspond to what would be observed in natural world settings*" (Kreutzer et al., 1996, p. 116). The items come from a wide spectrum of post-injury behaviours and symptoms commonly encountered in daily life. The authors therefore focus on ecological and content validity as being very important for the NFI.

Factor-analytical and validation studies took place in a large sample of 520 severely brain injured people who were on average 2.9 years post-injury. Principal components and confirmatory factor analysis identified six scales with a total of 70 out of the original 105 items. Internal reliability

for all scales ranged between 0.86 and 0.95. The scales were labelled as follows: depression, somatic, attention/memory, communication, aggression, and motor. Poor neuropsychological test performance and greater levels of psychopathology (as measured by the MMPI) were associated with more perceived neurobehavioral problems, confirming that the NFI has satisfactory criterion validity. Frequency of problem occurrence is rated on a 4-point scale: never, sometimes, often, always. The NFI has now been used in a number of studies by Kreutzer and his group (e.g. Kreutzer, Marwitz, and Witol, 1995; Witol, Sander, Seel, and Kreutzer, 1996) Two versions of the NFI exist: one for the patient, and one for the carer.

Nottingham Adjustment Scale - Self-esteem Subscale

The self-esteem subscale of the Nottingham Adjustment Scale is a modified version of the Rosenberg Self-esteem Questionnaire. Dodds, Flannigan, and Liza (1993) studied the effects of visual impairments on adjustment in a group of 425 visually impaired people. They found that 9 items loaded on the factor 'self-esteem'. Dodds, Bailey, Pearson, and Yates (1991) found that reducing the 10 items of the Rosenberg Scale to 9 items increased the homogeneity of the scale. Cronbach's alpha for the modified self-esteem subscale was 0.91. The resulting questionnaire is short and easy to understand with brief statements such as "*At times, I think I am no good at all*". This, and the fact that the Rosenberg Self-esteem Scale has been shown to have sufficient validity and reliability, is why the NAS self-esteem subscale was chosen for this study.

The NAS – Self-esteem scale can be found in appendix 5.4. Both the self-esteem subscale and the acceptance of illness scale were given at the same time. Self-esteem and acceptance items were given alternately, the first item from the self-esteem subscale, the following item from the acceptance of illness scale, the next self-esteem, etcetera.

Acceptance of Illness Scale

The Acceptance of Illness Scale (Felton and Revenson, 1984) is a shortened version of the Acceptance of Disability Scale, developed by Linkowski (1971). It consists of eight items which are rated on a 5-point agree-disagree continuum. Examples of items are: "*I have a hard time adjusting to my illness*", and "*Because of my illness, I miss the things I like to do most*". The shortened Acceptance of Illness Scale has been used as an adjustment measure in studies investigating the effects of illness (Felton and Revenson, 1984), Rheumatoid Arthritis (Revenson and Felton, 1989), Parkinson's Disease (MacCarthy and Brown, 1989), and Motor Neurone

Disease (Hogg, Goldstein, and Leigh, 1994). Validity and reliability have not been properly looked at for the shortened version. Felton and Revenson (1989) reported an internal consistency value of .83 and .81 on two different occasions, six months apart.

For use in this study, the word 'illness' was substituted with the words 'traumatic brain injury'. The 'acceptance of Illness scale' can be found in appendix 5.5. Both the self-esteem subscale and the acceptance of illness scale were part of the same questionnaire. Self-esteem and acceptance items were presented alternately, the first item from the self-esteem subscale, the following item from the acceptance of illness scale, the next self-esteem, etcetera. The self-esteem subscale consists of 9 items and the acceptance of limitations subscale consists of 8 items.

Satisfaction with Life Scale

The Satisfaction With Life Scale (Diener, Emmons, Larsen, and Griffin, 1985) was used as the main measure of subjective quality of life. The Satisfaction With Life Scale was designed to measure *cognitive* judgements of life satisfaction rather than *affective* judgements (Diener, 1993). It assesses satisfaction with the respondent's life as a whole (Pavot and Diener, 1993) and consists of five statements that can be agreed or disagreed with on a 7-point scale. It has been very widely used, in many different populations, and in many different cultures (Pavot and Diener, 1993). It has proven reliability and validity, established in many different studies (Pavot and Diener, 1993). Furthermore, it has shown "cross-situational consistencies and temporal stability" (Diener, 1993; pp. 105).

Question five of the SWLS ("*If I could live my life again, I would change almost nothing*") may not contribute to the general satisfaction factor, given the fact that the brain injured person may actually be to blame for the accident, and therefore would disagree with the statement, despite the fact that he may be happy at the moment. On the other hand, there does not seem to be a significant difference between the answers given by the severely brain injured people and the non-clinical sample on this question (see section 7.3.). Furthermore, leaving this item out, did not dramatically increase Cronbach's alpha (from .88 to .91) for the SWLS in the brain injured group. The same was true for the non-clinical sample (Cronbach's alpha went up from .88 to .90). Furthermore, all the analyses were executed with both the SWLS *with* and *without* question 5. This did not yield any different results.

The *Domain-specific Life Satisfaction Scale*, the *Life Priority Scale*, and the *Future Expectations Scale* were specifically designed for this study and will be discussed in the next chapter.

5.5. PARTICIPANTS

5.5.1. Brain injured participants

5.5.1.1. PROCEDURE

At the outset of the study, inclusion criteria were formulated They were the following:

- Male; most people who sustain a traumatic brain injury are men. This point is explained further below.
- Between 18 and 40 years old; This point is explained further below.
- At least one year post-injury; The one-year post-injury mark was chosen in order to get a good range of length of recovery, in order to be able to include time post-injury in the analyses and because by one year post-injury, cognitive and physical recovery should have largely levelled out.
- No severe communication problems; otherwise they could not be interviewed because the tape could not be transcribed.
- Must have the ability to verbalise thoughts and feelings; otherwise the interview would not yield any relevant information.
- Must have had consequences from the traumatic brain injury; otherwise there would not be anything to adjust to.
- Post traumatic amnesia more than one day; Russell's (1932) criteria suggested that a PTA of more than 1 day can be classified as a 'severe' head injury. However, van Zomeren's research suggested that a PTA of 13 days was a better cut-off point between moderate and severe head-injuries. A PTA of more than 1 day therefore includes both moderate and severe head injuries. The focus of this is therefore primarily with people who have suffered a moderate to severe traumatic brain injury.
- No prior history of psychiatric or neurological problems

The brain injured sample only included men between 18 and 40. This restriction in terms of the sample was chosen for the following two reasons:

Firstly, the present study is interested in *subjective* recovery. Many factors can possibly influence subjective status, including demographic, social, personal, and environmental factors. By only including men between 18 and 40 (who make up the biggest contingent of the entire brain injured population), it was anticipated that factors which have to do with age and sex would not influence the results and that therefore the reliability of the results would increase. It was felt that the more homogeneous the sample was, the more reliable the results would be.

Secondly, from a practical point of view, young adults are most likely to suffer a head injury (Jennett, 1996) and they are most likely to be still in contact with head-injury services. It was felt that rather than having a skewed brain injured sample (in terms of age and gender), the fact that more young adults are available to services could be turned into an advantage, namely by providing a more homogeneous research group.

The brain injured sample was recruited through local branches of HEADWAY, the National Head Injuries Association, and two clinical practices (Dr Freda Newcombe and Dr Neil Brooks).

Local HEADWAY groups were approached (Gloucester, Northampton, Bedford, and Swindon). Coordinators provided a list of possible individuals who were subsequently approached by the researcher. Twenty three patients agreed to participate this way.

Six patients from Dr Neil Brooks' practice and 20 from Dr Freda Newcombe's practice were recruited. They had all been assessed for medico-legal purposes. First, a letter was sent to their solicitor asking for permission to approach their clients. Then they were telephoned by the researcher to ask them for their participation.

Altogether, 56 brain injured people were approached and asked to participate in the study.

- One brain injured person refused to take part.
- The mother of one patient thought it would not be a good idea at this moment in time, given the fact that he was going through a difficult period.
- Furthermore, three brain injured people who did not want to be interviewed but who said they did not mind filling in the questionnaire ultimately did not return them.

This left 51 brain injured people who participated in the study. Of these, two more were dropped.

- One turned out not to have suffered a severe traumatic brain injury. His post traumatic amnesia was estimated to be a matter of minutes/hours rather than days.
- The second one turned out to have severe communication difficulties. He also did not seem to have filled in the questionnaires in a way that suggested conscious decisions (i.e. he gave the same answer to all the questions).

Two brain injured people agreed to take part in the study, but did not want to be interviewed. A further three wanted to take part, but now lived too far away to be interviewed. These five people were therefore sent the questionnaires by post and asked to return them in a prepaid envelope. They also identified carers who were willing to fill in the questionnaires.
All in all, 49 brain injured people and their carers decided to take part in the study.

44 qualitative interviews were carried out. The actual number of qualitative interviews used was 36 brain injured people and 36 carers. There are a number of reasons for the fact that 8 interviews were not used.

- Firstly, the four pilot interviews were not used.
- Secondly, some interviews were too difficult to transcribe because of communication difficulties.
- Finally, technological difficulties with the taperecorder also resulted in the loss of two interviews.

To summarise, 49 brain injured people and their significant others filled out the questionnaires, and of those 49, 36 brain injured patients and their significant others were also interviewed.

5.5.1.2. DEMOGRAPHICS

Table 5.2. shows the mean age, time post-injury and post traumatic amnesia (in days) of the brain injured group.

The average time post-injury was 7.74 years. The range was between 1.13 and 17.43 years.

TABLE 5.2. Age, time post-injury, and post-traumatic amnesia of the brain injured sample

	Mean	Median	S.D.	Min.	Max.
Age	29.79	28.47	4.77	22.37	41.54
Time post-injury	7.74	7.78	3.54	1.13	17.43
post traumatic amnesia	57.76	42.00	50.46	2	180

Post traumatic amnesia was established retrospectively in all cases. This is considered to be a reliable method of assessing post traumatic amnesia. It has been found that there is a very high correlation (r = .87) between prospective and retrospective assessment of post traumatic amnesia (McMillan, Jongen, and Greenwood, 1996). In that study, the interviewer was a medical student without any previous experience with head injuries. Furthermore, these researchers found that the reliability of establishing post traumatic amnesia did not diminish over time.

In 26 cases, post traumatic amnesia was obtained from the neuropsychological report. In 16 cases post traumatic amnesia was established in a short interview with the carer. In a further seven cases not enough information was available to make a reliable estimation of post traumatic amnesia.
The average post traumatic amnesia was 57.76 days. In terms of Russell's (1971) classification, this can be considered 'extremely severe'.

Figure 5.1. shows the distribution of post traumatic amnesia over the brain injured sample. It shows that the distribution of post traumatic amnesia is skewed towards the lower end.

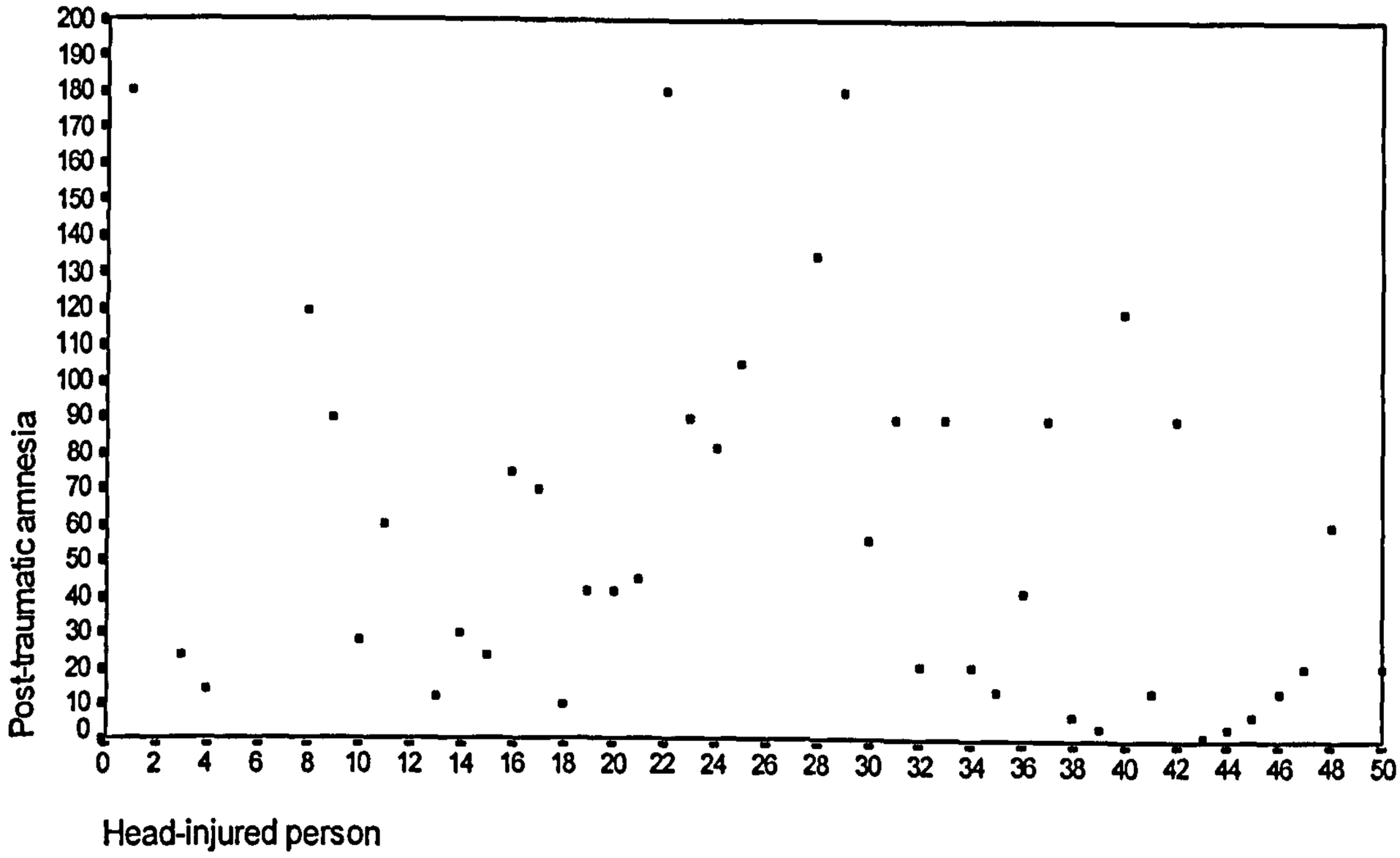

FIGURE 5.1.. The distribution of post-traumatic amnesia over the brain injured sample.

More than 3/4th of the brain injured sample did their 'O' levels, or an equivalent (table 5.3.).

Table 5.3. Education level of the brain injured sample

	Frequency	Percentage
No formal education	3	6.1
'O' levels; GCSE's; Vocational	37	75.5
'A' levels; HNC; C & G	6	12.2
Degree or higher	3	6.1

Table 5.4. Marital status of the brain injured sample

	Frequency	Percentage
Single	30	61.2
Married	9	18.4
Girlfriend/cohabiting	7	14.3
Divorced/separated	3	6.1

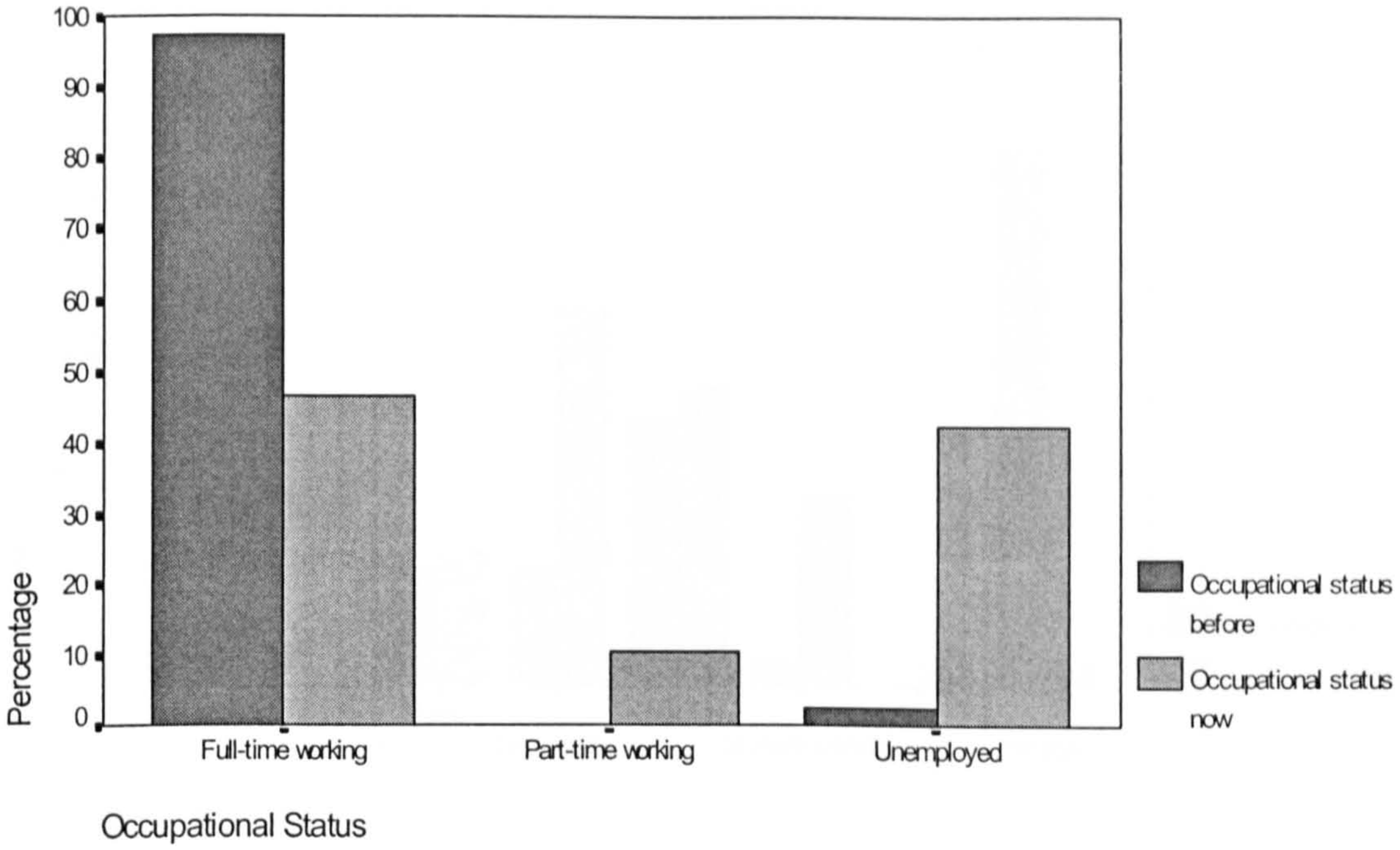

FIGURE 5.2. Occupational status before and after the accident

Figure 5.2. shows the occupational status before and after the accident. It clearly shows a large reduction in working status, with significantly more brain injured people being unemployed after than before the accident. This was confirmed by a non-parametric Wilcoxon test ($z = -4.59$; $p < .001$).

Figure 5.3. shows the type of occupation before and after the accident. It shows that the *level* of work has decreased slightly, i.e. when people do go back to work, they tend to do work at a slightly lower level. These data are clouded however, by the number of people who were at school/university before the accident, and the high number of people who were unemployed after the accident. Definite conclusions are therefore difficult to draw from these data.

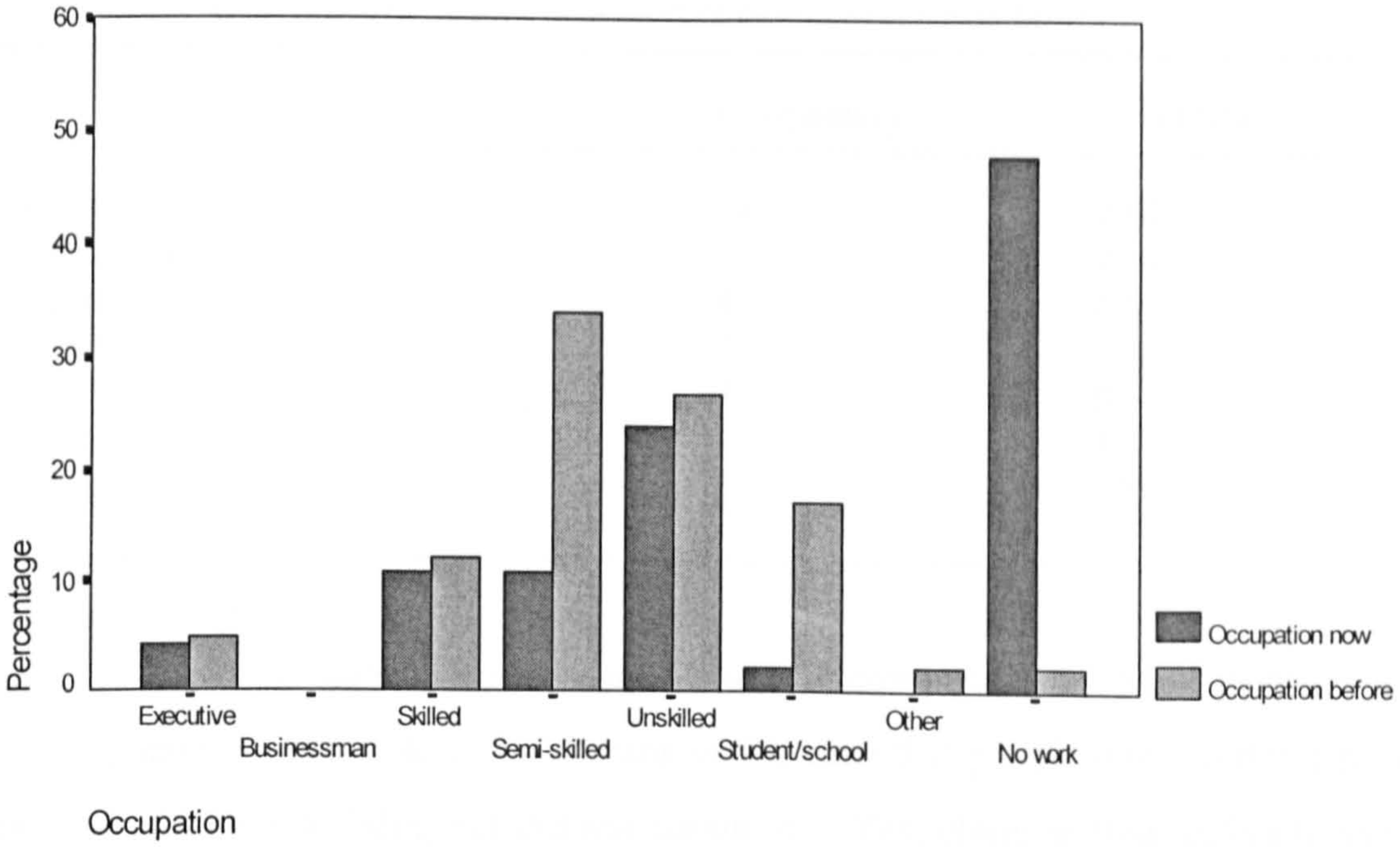

FIGURE 5.3. Level of work before and after the accident

Table 5.5. shows the living arrangements of people in the brain injured sample. Most people were still living at home, and only a small number of people lived in sheltered or supported accomodation.

TABLE 5.5. Living arrangements of the brain injured sample

	Frequency	**Percentage**
Lives with parents/family	20	40.8
Lives in own house/flat	15	30.6
Rents a house/flat	8	16.3
Residential/nursing home	4	8.2
Missing	2	4.1

Table 5.6. shows the cause of the accident which resulted in the traumatic brain injury. Most cases were the result of road traffic accidents (85.1%). This is consistent with reports in the literature that around 80% of all traumatic brain injury cases are caused by road traffic accidents (Jennett, 1995).

TABLE 5.6. Cause of the accident which resulted in a head-injury

	Frequency	Percentage
RTA driver	14	29.8
RTA passenger	11	23.4
RTA pedestrian	4	8.5
RTA motorbike	7	14.9
RTA bicycle	4	8.5
Assaults	2	4.3
Fall	5	10.6

Table 5.7. shows the state of the insurance claim for compensation. Most participants did have a claim to pursue (73%). 'No claim' means in this case that people either did not have a claim to pursue, or did have a claim, but did not pursue it. 'Yes, claim settled' refers to the situation in which the brain injured person had gone to court, or settled outside court, and had received compensation. 'Yes, but no settlement yet' refers to the situation in which the brain injured person was still pursuing a claim, but had not received any compensation yet.

TABLE 5.7. State of the insurance claim for the brain injured sample

	Frequency	Percentage
NO claim	12	26.7
YES claim settled	23	51.1
YES, but no settlement yet	10	22.2

Table 5.8. shows the relationship of the carer to the brain injured person. Thirty four carers were interviewed, and 41 carers filled in the questionnaires. Most were parents of the brain injured person.

TABLE 5.8. 'Significant other' who was interviewed and who filled in the carer's questionnaires

	Interview		Questionnaire	
	Frequency	Percentage	Frequency	Percentage
Mother/father	28	82	33	80
Girlfriend/wife	6	18	6	15
Friend	-	-	1	2.5
careworker	-	-	1	2.5
Nobody	15		8	

5.5.2 Healthy, non-clinical control group

5.5.2.1. PROCEDURE

People without head injuries were recruited in two different ways.

Firstly, a list of (male) personnel was obtained from people working at Oxford Brookes University. The list only included people who were not attached to a university department in the role of lecturer or researcher. Instead, they included people from departments such as 'catering', or 'buildings and estates'. They were promised two pounds if they returned the questionnaire. 52 questionnaires were sent out by post. 23 were returned, which is a response rate of 44%.

Questionnaires were also handed out to men in the reception area of the Department of Social Security (DSS) in Oxford. This was done to get responses from unemployed non-brain injured people. People who were waiting for an appointment were asked to fill in a questionnaire. They were given 2 pounds for doing so. 45 people were approached and 27 agreed to participate. This is a response rate of 60 %.

Overall, 50 controls filled out the questionnaires and the response rate was 51.5%.

The controls were asked to fill out the following questionnaires:

- Demographic variables

- The Life satisfaction Scale
- The Satisfaction with Life Domains Scale
- The Life Priority Scale
- The Future Expectations Scale

5.5.2.2. DEMOGRAPHICS

The brain injured sample and the non-clinical sample were compared on a number of demographic variables. Table 5.9. shows the two groups in terms of age, education, occupational and marital status. No *statistical* significant differences were found between the two groups in terms of age (t-test), or education and occupational status (Kruskal-Wallis Independent samples test).

The two groups were subdivided into 'single' and 'not single'. An independent samples Mann-Whitney test also failed to find a statistically significant difference between the two groups.

It would therefore seem that the brain injured group and the health control group were matched in terms of age, education, occupational and marital status.

TABLE 5.9. A comparison between brain injured people and a non-clinical sample in terms of demographic variables.

	Brain injured		Controls	
N	49		50	
Age	29.86 (s.d. 4.75)		29.28 (s.d. 5.53)	*Not Significant*
Education				*Not Significant*
No formal education	3	6.1 %	6	12.8 %
'O' levels	37	75.5 %	21	44.7 %
'A' levels	6	12.2 %	11	23.4 %
Degree	3	6.1 %	9	19.1 %
Occupational status				*Not Significant*
Full-time	22	45.8 %	23	46.9 %
Part-time	5	10.4 %	7	14.3 %
Unemployed	21	43.8 %	19	38.8 %
Marital status				*Not significant*
Single	30	61.2 %	25	(51.0 %)
Married	9	18.4 %	9	(18.4 %)
Girlfriend/cohabiting	7	14.3 %	13	(26.5 %
Divorced	3	6.1 %	1	(2.0 %)
Other	0	0.0 %	1	(2.0%)

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CHAPTER SIX The Satisfaction with Life Domains Scale for Traumatic Brain Injury

6.1. INTRODUCTION

The introductory chapters have shown that there is a lack of research into brain injured people's subjective perceptions of their own situation. This lack of studies is compounded by (or partly the result of) the fact that the appropriate tools to measure subjective perceptions do not exist yet or have not previously been used in the context of traumatic brain injury.

This chapter describes the development of three new questionnaires: The Satisfaction with Life Domains Scale for Traumatic Brain Injury, The Life Priority Scale, and The Future Expectations Scale. They were specifically designed to be able to obtain a quantitative measure of the brain injured person's subjective status.

6.2. PSYCHOMETRIC REQUIREMENTS

Any good measure of outcome should meet certain psychometric requirements. In this section those requirements will be described.

Questions of ***validity*** ask whether an instrument actually measures what it purports to measure. Validity is usually considered in terms of content, criterion, construct as well as face and clinical validity.

Content validity refers to the question whether dimensions and single items cover all relevant aspects of the particular concept to be measured. It is about the 'representativeness or sampling-adequacy of the content purportedly measured by the new scale' (Albrecht, 1994). Establishing content validity is a non-statistical, subjective procedure.

Criterion validity concerns the question of whether the new measure correlates with some superior criterion, an outside 'gold standard' or benchmark. Unfortunately, gold standards do not exist for outcome measures. There is usually no way of getting an objective, direct and 'true' score of the construct one purports to measure. Criterion validity - or rather, the criterion against which the new measure is compared - therefore usually takes two forms.

First, the criterion can be another measure with accepted validity, purporting to measure the same construct (concurrent validity). This is a rather weak way of assessing validity, since both the new and the older measures may correlate, yet neither assesses the underlying construct correctly.

The ability to predict future success in a certain field is sometimes taken as another criterion (predictive validity). For example, measures of physical functioning may predict mobility in the community. Predictive validity has special importance for clinicians, for they require measures that tell them something about how the patient performs outside the clinical setting or how they will perform in the future.

The underlying concept of a certain scale is usually not measurable directly. For example, there is no direct way to measure how depressed an individual is. However, it is possible to make predictions from the underlying constructs of a measure and put these to the test. This way of assessing validity is called construct validity. It "*refers to the power, adequacy and precision of the constructs that theoretically underpin the actual measurement instruments*" (Albrecht, 1994). An example of this would be the prediction that people with low scores on a new test of depression, should also score low on the number of social activities they enjoy and should score high on insomnia and eating disturbances. If the correlation of the new test and these scores fails to produce significant results, then this new test is said to be low *in construct validity*.

Face validity refers to the sensibility and acceptability of dimensions and single items for both user and subject (Rust and Golombok, 1989). Scores on a particular scale are worth nothing if questions are ambiguous, not easily understood or patients do not take them seriously because they do not make sense to them.

Clinical validity concerns the question of whether a measure is able to distinguish between patients with different diagnoses and between different degrees of disease severity within a given diagnosis. It also asks whether a measure is sensitive to change. More will be said later about this latter topic.

Assessment of the ***reliability*** of a new measure addresses the question of whether this measure is accurate across time and contexts (Albrecht, 1994). Any score consists of a true component, a systematic error component and a random error component (Hays, Anderson and Revicki, 1993). Both the true score and the systematic bias contribute positively to the reliability, the random error reduces reliability.

Evaluation of reliability usually takes three forms.

In the case of *test-retest reliability*, the same test is administered twice within a certain time-span. These scores are then correlated for every subject. The higher the correlation between each individual's scores, the higher test-retest reliability is said to be. In this case, reliability is calculated across time, for the same subject. Test-retest reliability is generally difficult to establish in patient groups, because it is uncertain whether any changes in scores between time A and B are due to a change in the patient's status or due to a high random error.

The second form of reliability is *interrater reliability*. In this case the same test is administered to participants by different examiners. The scores of the two populations are then correlated and yield a reliability score. In this case, reliability is calculated for different examiners.

Finally, *internal consistency* is the extent to which items within a particular dimension covary. The higher the internal consistency, the more the probability of random error decreases.

There are some ***practical requirements*** for a good measure of outcome.

If a measure is to be regularly used within a clinical setting, then it should be short and simple to administer, score and interpret.

Furthermore, the information the patients give in a measure should be as reliable as possible. The questions should therefore be unambiguous and relevant to the subject. Also, the entire test should be short and not be too burdensome for the patient.

6.3. DEVELOPMENT OF THE SATISFACTION WITH LIFE DOMAINS SCALE

The Satisfaction with Life Domains Scale for traumatic brain injury (SLDS-TBI) was designed to measure a person's subjective evaluation of his life in general and of specific areas of his life in particular. As such, it fits in with other attempts at measuring subjective, rather than objective quality of life (Baker et al., 1992). It is thought that people's own opinions and perceptions of their situation are "*as important.....as is the absence of signs and symptoms used to define the disorder*" (Endicott, Nee, Harrison, and Blumenthal, 1993). An effort was therefore made to avoid items which measure common symptoms and neuro-behavioural problems that follow traumatic brain injury. Instead, the SLDS-TBI focuses on items which are relevant to the brain injured person's personal and social needs, namely on those factors which are often associated with increased or decreased general satisfaction, happiness or well-being in patient groups or in the general population.

The 16 life domains included in the SLDS-TBI were selected on the basis of a review of the relevant literature in the following fields.

1. General Quality of Life Measures

The general literature on quality of life was reviewed. Appendix 6.1. lists a number of studies in the field of generic measured of quality of life, mental illness, and epilepsy. It also lists all the domains included in quality of life measures used in different fields.

2. Other Measures of Domain-specific Life Satisfaction

Existing measures of domain specific life satisfaction were reviewed. Viitanen, Fugl-Meyer, Bernspång, and Fugl-Meyer (1988) looked at the impact of stroke on life satisfaction with a 6-item scale. Using an extended measure of nine items, Viitanen, Lundmark, Mansson, and Fugl-Meyer (1996) compared four groups (spinal cord injury, multiple sclerosis, stroke, and a reference group) in terms of their satisfaction with different life domains. The domains they

adopted were: life as a whole, self-care, leisure, vocational situation, financial situation, sexual life, "partnership relation", family life, and contacts with friends and acquaintances.

Baker, Curbow, and Wingard (1992) developed a scale for use with cancer patients. Their scale contained 18 items (health, relationship with partner, relationships with relatives, relationships with friends, one's body, the ability to go about daily activities, job/school/household work, leisure, appearance, physical strength, how comfortable one feels overall, sexual satisfaction, ability to eat, ability to control personal circumstances, the quality of life, the future, life as a whole).

Baker and Intagliate (1981) designed a Satisfaction with Life Domains Scale for patients with chronic mental illness. Their scale contained 15 items (satisfaction with housing, neighbourhood, food to eat, clothing, health, people lived with, friends, family, relations with other people, work/day programming, spare time, fun, services and facilities in area, economic situation, place lived in now compared to state hospital, and total life satisfaction score).

Davis, Davis, Moss, Marks, McGrath, Hovard, Axon, and Wade (1992) described a scale they are using in a clinical setting to focus on what clients reported to be the most important aspects of their life. Their scale contained nine items (the importance of residential and domestic arrangements, the ability to manage personal care, leisure/hobbies/interests, work, relation with partner, family life, contacts with friends, neighbours and acquaintances, religion and financial status).

3. Predictors and Causes of Happiness

The literature on causes and factors influencing happiness and well-being in the general population was important in influencing the development of the SLDS-TBI. Diener (1984) suggested that the domains that are closest and most immediate to people's personal lives are those that most influence subjective well-being. Table 6.2. lists the causes of happiness as reported by different authors.

Table 6.1. The causes of happiness according to different authors

Author(s)	Variable	Causes
Campbell et al. (1976)	Satisfaction	Family life; Marriage; Financial situation; Housing; Job; Friendship; Health; Leisure activities;
Diener (1984)	Well-being	Satisfaction with self; Age; Religion; Employment; Social contact; Activities; Personality;
Argyle and Martin (1991)	Joy	Social contacts; Sexual activity; Success, achievement; Physical activity/exercise/sport; Nature/reading/music; Food and drink; Alcohol
Headey and Wearing (1992)	Well-being	Marriage; Sex; Friendship; Leisure; Material standard of living; Work; Health;
Ryff and Keyes (1995)	Well-being	Self-acceptance; Environmental mastery; Positive relations; Purpose in life; Personal growth; autonomy;
e.g. Argyle (1987)	Happiness	Extraversion; low in neuroticism;

What is clear is that both very practical, day-to-day concerns (such as work, financial situation, social contacts and activities) and 'higher' concerns, to do with the way a person feels about himself and his place in the world (such as self-esteem, religion, autonomy and purpose in life) seem to influence happiness.

Baker, Curbow, and Wingard (1992) set out a number of standards for the development of their instrument, the 'Satisfaction with Life Domains Scale for Cancer'. These have been adopted for the purposes of this study. They are:

1. It is a self-report measure that allows patients to rate their own subjective satisfaction with their lives.
2. It samples a wide range of life domains likely to be affected by cancer and its treatment.
3. The wording and response format should be easy to understand.
4. It should be easy to complete.
5. It should be acceptable to patients.
6. It should allow expression of both positive and negative ratings of aspects of life.
7. It should demonstrate adequate reliability and validity.
8. It should be based on a modification of quality of life assessment procedures developed with non-brain injured populations rather than be entirely ad hoc in nature.

The SLDS-TBI was designed on the basis of the fields in the literature described at the beginning of this section and on the basis of the standards set out by Baker et al. (1992). Table 6.3. lists the selected domains of the SLDS-TBI. It includes day-to-day concerns, as well as higher aspirations. It contains items related to oneself and also to the way a person interacts with the outside world. It is therefore thought to be a fairly comprehensive measure of important factors in a person's life.

The SLDS-TBI is scored on a six point scale, ranging from 'very dissatisfied' to 'very satisfied'. A middle category ('neither satisfied nor dissatisfied' or 'don't know') was not included in order to force the subject to make either a positive or a negative choice.

Two versions of the SLDS-TBI exist: one for the brain injured person and one for his or her significant other.

A copy of the SLDS-TBI can be found in appendix 5.4.

Table 6.2. Domains of the Satisfaction with Life Domains Scale for Traumatic Brain Injury

Domains of the SLDS-TBI	
◻ Ability to take care of oneself ◻ Level of independence ◻ Physical abilities ◻ Mental abilities ◻ Leisure opportunities ◻ Work/educational situation ◻ Financial situation ◻ Relationship with partner ◻ Not having a relationship with a partner	◻ Family life ◻ Contacts with friends ◻ Sexual life ◻ The way days are spent ◻ Aims and purposes in life ◻ The way one feels about oneself ◻ Religious / spiritual life ◻ Life as a whole

6.4. METHODS

6.4.1. Participants

The SLDS-TBI was given to a sample of first-year undergraduate students (N = 126). In order to determine test-retest reliability, they filled in the questionnaire again three weeks later. The mean age of this sample was 22 years old (standard deviation 5.8). The sample included 84 women and 42 men.

The SLDS-TBI was also given to a sample of 49 brain injured people and also to 50 people from the non-clinical sample described in section 5.5.2.

6.4.2. Protocol

The SLDS-TBI was piloted in a small group of healthy people, mainly nurses, and in a small group of brain injured people and their carers. The Scale was then given to a sample of first-year students, the healthy control group, and was also included in the questionnaire battery that was filled in by 49 brain injured people and their carers.
The student sample also filled in the Hospital Anxiety and Depression Scale (HADS) and the brain injured people and their carers also filled in the HADS and the Satisfaction with Life Scale (Diener, 1985; Pavot and Diener, 1993).

The SLDS-TBI items were summed to obtain an overall score. Not included in the sum score was the question: "*how do you feel about your life as a whole*". The possible sum score ranged from 16 to 96. The actual obtained range for the student sample was 39 to 89.

6.4.3. Reliability and Validity

Validity and reliability were determined as follows:

1. A pilot study in a small group of healthy people, mainly nurses, and in a small group of brain injured people and their carers to determine *face validity*

2. As described previously, c*ontent validity* was established by a thorough literature search in the following areas:
    a. Domain-specific quality of life measures
    b. Measures of domain-specific life satisfaction
    c. Predictors and causes of happiness
3. Cronbach's alpha measures how well a set of items (or variables) measures a single uni-dimensional latent construct. Cronbach's alpha for the student sample was .81, indicating a satisfactory reliability. In the brain injured group (N = 49), Cronbach's alpha was .91. This shows that there is a high internal consistency of items in the scale. The reliability of the scale was not improved by deleting any of the items[1].
4. *Test-retest reliability* of the SLDS-TBI was established in the sample of first-year students. The interval between measurements was three weeks. The obtained test-retest reliability for the sum-score was .82 ($p < .001$). Test-retest reliability for individual items ranged between .50 ("*How do you feel about your physical abilities*"; "*How do you feel about your leisure opportunities*"; "*How do you feel about your contacts with friends*") and .83 ("*How do you feel about your life as a whole*"). See table 6.3.
5. The sum-score of the SLDS-TBI was significantly and negatively related to HADS-anxiety ($r = -.35$; $p < .01$) and HADS-depression ($r = -.34$; $p < .01$) in the sample of students.

All individual items were negatively and significantly related to HADS-anxiety, except satisfaction with physical abilities, work/educational situation, relation with partner, not having a relation with a partner, family life, and sexual life.

Most individual items were negatively and significantly related to HADS-depression, except satisfaction with physical abilities, relation with a partner, not having a relation with a partner, family life, sexual life, and religious life.

In the brain injured group, the sum-score of the SLDS-TBI was highly significantly correlated with HADS-anxiety ($r = -.57$; $p < .001$), HADS-depression ($r = -.79$; $p < .001$), and the Satisfaction With Life Scale ($r = .81$; $p < .001$).

These results show that the SLDS-TBI has *satisfactory criterion validity*

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[1] There is not a generally agreed cut-off point for Cronbach's alpha. Usually 0.7 and above is acceptable (Nunnally, 1978). In the social sciences, an alpha level of 0.8 is often accepted and was adopted in this study.

A factor analysis of the student sample did not yield any obvious groupings of the different domains. The test statistics of the factor analysis can be found in appendix 6.2.

6.5. THE LIFE PRIORITY SCALE

The Life Priority Scale (LPS) was designed in order to investigate the relative importance of specific domains on people's well-being (see section 4.8 on 'the relativity of quality of life').

The LPS consists of 15 questions of the type: "*How important is X for you*?". X stands for a particular domain in their life. The domains chosen for the LPS are exactly the same as those of the SLDS-TBI. Individuals can rate themselves on a six-point scale ('very unimportant'; 'unimportant'; 'rather unimportant'; 'rather important'; 'important'; and 'very important').

The LPS is to be used to investigate any shifts which may have taken place in the relative importance of domains by comparing answers given by brain injured people to those given by control groups. The goal is therefore to identify whether, following their accident, brain injured people have different priorities from healthy controls or people with a different chronic illness.

A copy of the Life Priority Scale can be found in appendix 5.4.

Cronbach's alpha for all the domains of the LPS (15) in the group of students was .84.

Table 6.3. Average ratings of the student sample on the satisfaction with Life Domains Scale, the Life Priority Scale, and the Future Expectations Scale.N = 126

	SATISFACTION		IMPORTANCE		FUTURE	
	s.d.	*test-retest*	*s.d.*	*test-retest*	*s.d.*	*test-retest*
Care	.82	.62	.82	.57	.62	.68
Independence	.89	.62	.71	.19	.71	.68
Physical Abilities	1.06	.49	.60	.39	.76	.65
Mental Abilities	1.10	.71	.67	.21	.77	.59
Leisure	1.26	.52	.81	.65	.89	.40
Work	1.25	.79	.79	.57	.94	.79
Finance	1.76	.74	.86	.55	.88	.71
Partner	1.43	.59	.85	.68	.78	.67
No Partner	1.59	.57	1.18	.58		
Family	1.55	.82	.95	.69	1.12	.82
Friends	1.11	.51	.78	.55	.74	.47
Sexual life	1.61	.71	1.07	.72	.78	.74
Spending days	1.09	.61	.92	.28	.74	.58
Aims and purposes	1.35	.75	.87	.34	.73	.58
Yourself	1.45	.66	.70	.44	.82	.51
Religious Life	1.13	.53	1.47	.81	1.60	.91
Happy					.63	.50
Hopeful					.96	.67

6.6. THE FUTURE EXPECTATION SCALE

The Future Expectations Scale (FES) was designed in order to be able to investigate brain injured people's perceptions of the future.

The FES consists of 16 questions of the type *"Do you think you will behave X in 5 years from now?"* X stands for a particular domain in their life. In cases where this format was inappropriate, the following format was chosen: *"Do you think you will be satisfied with your X in 5 years from now?"*.

The first type of question included the domains personal care, independence, work, finances, relationship, sexual life, spending days usefully, and religious life.

The second type of questions included the domains physical abilities, mental abilities, leisure activities, family life, and friendships.

The domains chosen for the FES were exactly the same as those of the SLDS-TBI. Participants were able to answer the questions on a six-point scale ('Definitely'; 'Probably'; 'Maybe'; 'Maybe not'; 'Probably not'; and 'Definitely not').

Two questions were added to the FES.

The first was *"Do you feel hopeful about the future?"* Participants were able to tick one of 6 possible responses ('definitely', 'very often', 'occasionally', 'occasionally not', 'quite often not', 'definitely not') This is a single-item measure of optimism/pessimism.

The second question that was added was *"Would you say you look more towards the past or the future?"*. Participants were able to tick one of 6 possible responses ('definitely the past', 'very often the past', 'occasionally the past', 'neither the past nor the future', 'occasionally the future', 'often the future', 'definitely the future'). 'The reason why this question was added is because it is hypothesised that one's orientation (past or future) is a marker for one's level of adjustment (see section 5.2. on research questions). This question can be answered on a 7-point scale.

A copy of the Future Expectations Scale can be found in appendix 5.4.

Cronbach's alpha for all the domains of the FES in the group of 126 students was .84.

Test-retest reliability ranged between .40 ("*Do you think you will have satisfying leisure activities in 5 years from now*?") and .91 *("do you think you will have a religious/spiritual life in 5 years from now*?"). The average test-retest reliability was .65 for all 17 domains (see table 6.3.).

Test-retest values for each item were correlated with the standard deviation per item. The correlation was .563 ($p = 0.015$). This suggested, similar to the previous section, that the test-retest reliability for some of the items was relatively low because participants only used some of the categories available to them to rate themselves.

A factor analysis of the student sample did not yield any clear groupings of the different domains.

6.7. DISCUSSION

The information on reliability and validity of the SLDS-TBI indicated that it meets the psychometric requirements necessary for a measure to be used in clinical or research settings. While there is no generally accepted gold standard, the high, positive correlation between the sum-score and the Satisfaction with Life Scale - a well-validated and reliable measure (Diener, 1985; Pavot and Diener, 1993) - and the high, negative correlation with anxiety and depression affirm the psychometric qualities of the SLDS-TBI. Both test-retest reliability (in a sample of students) and the internal consistency reliability (in a sample of students and in a sample of brain injured people) are satisfactory.

Knowledge of which particular areas in a person's life are affected by traumatic brain injury can be used in a clinical setting to focus attention and resources on those domains of a person's life that he is particularly dissatisfied about. Different rehabilitation strategies may be needed for dissatisfaction with different areas of a person's life. More therapeutic interventions may be considered when a person experiences dissatisfaction with self, aims and purposes in life, sexual life, family life and relation with a partner or lack of a relation with a partner. More practical interventions may be required in the case of dissatisfaction with a person's ability to take care of himself, leisure opportunities, work/educational situation, financial situation, and the way he spends his days. The SLDS-TBI can thus be used in addition to more traditional ways of assessment.

The SLDS-TBI not only shows domains within an individual's functioning which are not going well, but also gives information on areas within his functioning that are going well, and that he is satisfied about. Clinicians may then exploit the positive features in the pattern of response.

The SLDS-TBI can not only be used to indicate where intervention may be required, but also to measure the impact of interventions or rehabilitation efforts over time. Future research is needed to examine the usefulness of the SLDS-TBI in this respect.

The SLDS-TBI also makes it possible to compare brain injured people with other populations, such as people with a different chronic illness or healthy controls. This will yield useful information on the long-term impact of traumatic brain injury on subjective perceptions.

Because the SLDS-TBI is a self-report measure of how the brain injured person perceives his own life, it can be used without norms. The brain injured person acts as his own, internal control (Schipper, 1990). Scores can be taken at face value to indicate areas of dissatisfaction or change over time.

CHAPTER SEVEN Long-term Subjective Quality of Life following Severe Traumatic Brain Injury

7.1. INTRODUCTION

This chapter is concerned with the first research question of this study: what is the long-term subjective quality of life of a sample of severely brain injured people?

Firstly, the responses of the brain injured group on the Satisfaction with Life Domains Scale will be analysed (7.2.).
The brain injured group's subjective status will be compared to that of a group of people who have not had a traumatic brain injury and who have been matched in terms of sex, education, occupational and marital status (section 7.3).
Differences between ratings of the carer and the brain injured person in terms of cognitive status and neuro-behavioural problems have often been found. Section 7.4. will explore whether they agree over the brain injured person's *subjective* status.
Finally, the main neuro-behavioural problems of the brain injured sample, as perceived by themselves and their carers, will be reported.

7.2. SUBJECTIVE QUALITY OF LIFE

This section is concerned with the question what domains brain injured people were most and least satisfied about.

Table 7.1. shows mean scores of the brain injured sample on domain-specific satisfaction. Two domains were in the 'dissatisfied' section (i.e. an average rating of less than 3.5), namely "*How do you feel about the fact that you do not have a partner*?" and "*How do you feel about your sexual life*?" The rest of the domains were all rated as 'rather satisfied' or higher.

A pair wise comparison was performed on all ratings of satisfaction (the Wilcoxon Signed Ranks Test) in order to determine which domains were rated as significantly less or more satisfying than the others.

In the brain injured group, not having a relationship and sexual life were rated as significantly lower in terms of satisfaction than almost all the other domains (see appendix 7.1, for a table of pair-wise comparisons between domains).

In the brain injured group, only 'ability to take care of oneself' was rated significantly higher than most of the other domains (see appendix 7.1.).

TABLE 7.1. Mean scores of brain injured people on the Satisfaction with Life domain-Scale for TBI.

	Mean	S.D.	Min.	Max.	N
Satisfaction with.....					
1. Ability to take care of oneself	4.96	1.22	1	6	48
2. Religious life	4.86	.75	3	6	37
3. Relationship with partner	4.78	1.31	1	6	18
4. Family life	4.53	1.38	1	6	45
5. Independence	4.15	1.62	1	6	46
6. Physical abilities	4.06	1.59	1	6	48
7. Friendships	3.96	1.61	1	6	48
8. Life in general	3.93	1.62	1	6	45
9. Mental abilities	3.87	1.48	1	6	48
10. Aims	3.87	1.48	1	6	47
11. Spending days	3.87	1.27	1	6	45
12. Yourself	3.78	1.55	1	6	46
13. Leisure	3.77	1.55	1	6	47
14. Financial situation	3.73	1.62	1	6	48
15. Work	3.66	1.67	1	6	47
16. Sexual Life	3.13	1.66	1	6	45
17. No Partner	2.14	1.25	1	6	29

7.3. COMPARISON BETWEEN THE BRAIN INJURED AND THE NON-CLINICAL SAMPLE

7.3.1. Global satisfaction

Table 7.2. shows the comparison between the brain injured sample and the control group on ratings of global satisfaction. The table includes the Satisfaction with Life Scale, a single question measure of global subjective quality of life ("*How do you feel about your life*"?) and the five individual items of the Satisfaction with Life Scale.

TABLE 7.2. Mean scores of brain injured people and a non-clinical sample on the Satisfaction with Life Scale Score

	Brain injured (N = 46)		Controls (N = 46)				
	Mean	s.d.	Mean	s.d.	t	df	
Satisfaction with Life Scale Score (0-35)	18.33	8.82	19.33	7.53	.58	90	ns
"How do you feel about your life?" (0-6)	3.93	1.62	4.25	1.19		90	ns

(a) ns not significant;

An independent samples t-test suggested that there was no difference between the two groups on the Satisfaction with Life Scale. A Mann-Whitney independent samples test[1] was used to compare the two groups in terms of their answers given to the question "*how do you feel about your life*?" No significant difference was found between the two groups[2].

To summarise, no significant differences were found between the brain injured sample and the matched control group in terms of their ratings of global satisfaction.

7.3.2. Domain-specific Satisfaction

[1] Non-parametric statistics were used for this comparison because the scoring of this question (from 'very dissatisfied' to 'very satisfied') was judged to be at ordinal level.
[2] Mean rank of the brain injured group: 44.96; Mean rank for the control group: 48.92; u = -.73; p = .47

Table 7.3. shows the means and standard deviations of the brain injured sample and the control group in terms of domain-specific life satisfaction.

Non-parametric statistics were used to compare the two groups. This was done because the scoring of the questions was judged to be at ordinal level[1] and also because many of the distributions of the domains of satisfaction were skewed and therefore did not approach a normal distribution.

Appendix 7.2. shows the mean ranks and the numbers of both the brain injured and the control group. Appendix 7.5. shows the two-tailed test statistics for the Mann-Whitney Independent Samples Comparison between the Brain injured group and the control group on the Satisfaction with Life Domains Scale.

TABLE 7.3. Means and standard deviations of the brain injured sample and the control sample on domain-specific evaluations of satisfaction.

	Brain injured N = 49				**Controls N = 50**				
	Mean	Median	N	s.d.	Mean	Median	N	s.d.	
Satisfaction with... (0-6)									
Aims	3.87	4.0	47	1.48	4.13	4.0	47	1.12	.
Ability to take care of oneself	4.96	5.0	48	1.22	5.22	5.5	49	.87	
Spending days	3.87	4.0	45	1.27	4.00	4.0	48	1.05	
Family life	4.53	5.0	45	1.38	4.27	5.0	49	1.51	
Financial situation	3.73	4.0	48	1.62	2.97	3.0	48	1.49	
Friendships	3.96	4.5	48	1.61	4.63	5.0	48	1.10	
Independence	4.15	4.5	46	1.62	4.96	5.0	49	1.06	
Leisure	3.77	4.0	47	1.55	4.55	5.0	49	.98	
Mental abilities	3.88	4.0	48	1.48	4.98	5.0	48	.86	*
Physical abilities	4.06	4.5	48	1.59	4.65	5.0	48	1.14	
Life without partner	2.14	2.0	29	1.25	3.81	4.0	16	1.49	
Life with partner	4.78	5.0	18	1.31	5.00	5.0	29	1.20	
Religious life	4.86	5.0	37	.75	4.39	5.0	41	1.38	
Sexual life	3.13	3.0	45	1.66	4.45	5.0	47	1.27	*
Work situation	3.60	4.0	47	1.67	3.66	5.0	48	1.25	
Yourself	3.78	4.0	46	1.55	4.43	5.0	46	1.20	

* indicates a significant difference

[1] The categories participants could score were: 'very dissatisfied', 'dissatisfied', 'slightly dissatisfied', 'slightly satisfied', 'satisfied', and 'very satisfied'. Because it is not clear whether the relative distance between the categories is the same, the categories used were judged to be at ordinal level, and non-parametric statistics were used.

A Bonferroni test for multiple comparisons was used for the comparison in terms of domain-specific life satisfaction in order to avoid making a type I mistake. The significant p-level was therefore .05/16 = .003.

It was found that the brain injured group was significantly less satisfied than the control group with their:

- mental abilities ($u = -.3.91$; $p < .001$)
- sexual life ($u = -3.80$; $p < .001$)

Brain injured people with a partner were as satisfied with their sexual life as controls with a partner [$u = -.97$; $p = .33$]. However, brain injured people without a partner were significantly less satisfied with their sexual life than controls without a partner [$u = -2.51$; $p = .01$].
It would seem, therefore, that brain injured people with a partner are as happy with their sexual life as controls with a partner, but that brain injured people without a partner are much less satisfied with their sexual life than controls without a partner. Not having a partner has a more than normal effect on how the person feels about this fact and how he feels about his sexual life.

It is striking to see that brain injured people were not more dissatisfied than the control group with their work/educational situation. Return to work is often an explicitly stated goal of rehabilitation efforts. However, from these data, it would seem that the subjective experience of work/education is the same for the brain injured and the non-brain injured people.

A comparison between the significant other's perception of the brain injured person's domain specific satisfaction and the control group corresponded largely with the comparison between brain injured and controls. All the domains (except financial situation) that were significantly different between the brain injured group and the control group were also significantly different between carers and controls. Moreover, the significant others rated the brain injured group significantly less satisfied about their aims and purposes in life than the controls rated themselves.

7.3.3. Values

Table 7.4. shows the ratings of the brain injured people and the controls on questions pertaining to how important they find specific domains in their life. The variation in the answers given was low, in both groups.

Appendix 7.3. shows the mean ranks and the numbers of both the brain injured and the control group. Appendix 7.5. shows the test statistics for the Mann-Whitney Independent Samples Comparison between the Brain injured group and the control group on Life Priority Scale.

No significant differences were found between the brain injured sample and the control group on the Mann-Whitney independent samples test. This suggests that the injury itself has not caused a shift in the brain injured group in terms of what they find important in their life.

TABLE 7.4. Mean scores of brain injured people and the control group in terms of their evaluations of the importance of specific domains

	Brain injured N = 49			**Controls** N = 50			
	Mean	Median	s.d.	Mean	Median	s.d.	
Importance of..... (0-6)							
Aims	5.00	5.0	1.01	5.19	5.0	.82	ns
Ability to take care of oneself	5.42	6.0	.94	5.31	5.5	.80	ns
Spending days	4.84	5.0	1.01	4.71	5.0	.84	ns
Family life	5.19	5.0	1.01	4.77	5.0	1.39	ns
Financial situation	5.32	6.0	.89	5.19	5.0	.82	ns
Friendships	5.11	5.0	1.10	5.00	5.0	.91	ns
Independence	5.42	6.0	1.01	5.49	6.0	.65	ns
Leisure	4.91	5.0	1.18	5.06	5.0	.83	ns
Mental abilities	5.50	6.0	.70	5.45	6.0	1.02	ns
Physical abilities	5.53	6.0	.69	5.22	5.0	.90	ns
A relationship	5.14	6.0	1.30	4.94	5.0	1.00	ns
Life with partner	5.43	6.0	1.09	5.71	6.0	.53	ns
Religious life	2.79	3.0	1.49	2.94	2.5	1.63	ns
Sexual life	4.64	5.0	1.37	4.98	5.0	.78	ns
Work situation	4.86	5.0	1.09	5.02	5.0	.91	ns
Feeling good about oneself	5.13	5.0	.98	5.14	5.0	.79	ns

(a) ns not significant;

7.3.4. Future expectations

Table 7.5. shows the average ratings of the brain injured sample and the controls on questions pertaining to their expectations of the future in different domains.
Appendix 7.4. shows the mean ranks and the numbers of both the brain injured and the control group. Appendix 7.5. shows the test statistics for the Mann-Whitney Independent Samples Comparison between the Brain injured group and the control group on the Future Expectations Scale.

A Bonferroni test for multiple comparisons was used for the comparison in terms of domain-specific life satisfaction in order to avoid making a type I mistake. The significant p-level was therefore .05/17 = .003.

The domains which brain injured participants rated significantly more pessimistically than the control group (at $p < .01$) were:

- Ability to take care of oneself ($u = -4.54$; $p < .001$)
- Independence ($u = -3.95$; $p < .001$)
- Work ($u = -4.00$; $p < .001$)
- Relationship with partner ($u = -3.64$; $p < .001$)

TABLE 7.5. Mean scores of the brain injured group and the control group in terms of domain-specific expectations for the future. The lower the score, the more optimistic the group is about that domain.

	Brain injured N = 45			**Controls N = 49**			
	Mean	Median	s.d.	Mean	Median	s.d.	
Future expectations..... (0-6)							
Aims	3.05	3.0	1.74	1.90	2.0	.94	
Ability to take care of oneself	3.16	2.0	2.07	1.38	1.0	.67	*
Spending days	3.05	3.0	1.64	2.29	2.0	.82	
Family life	3.04	3.0	1.86	2.51	2.0	1.50	
Financial situation	2.74	2.0	1.51	2.73	3.0	1.23	
Friendships	3.00	3.0	1.75	2.15	2.0	1.05	
Independence	3.47	4.0	1.94	1.90	2.0	1.07	*
Leisure	3.07	3.0	1.63	2.08	2.0	.70	
Life in general	3.14	3.0	1.66	2.36	2.0	.94	
Mental abilities	2.93	3.0	1.70	1.90	2.0	1.04	
Physical abilities	3.12	3.0	1.85	2.13	2.0	.98	
Life with partner	3.11	3.0	1.60	1.94	2.0	.73	*
Religious life	3.65	3.0	.76	4.10	5.0	1.74	
Sexual life	3.07	3.0	1.64	2.00	2.0	.97	
Work situation	3.39	3.5	1.83	1.86	2.0	.71	*
Yourself	3.18	3.0	1.68	2.25	2.0	.96	
Hopeful about the future	3.00	3.0	1.62	2.63	2.0	1.28	

* indicates a significant difference

These comparisons show that brain injured people generally had more negative expectations of the future in some of the domains.

In a comparison of a more global question of future expectations ("*Do you feel hopeful about the future*?"), which can be taken as a global measure of optimism/pessimism, the brain injured group and the control group did not differ significantly.

7.4. COMPARISON BETWEEN THE BRAIN INJURED PERSON AND HIS SIGNIFICANT OTHER

The brain injured person's rating of his own subjective quality of life was compared with the significant other's ratings of his subjective quality of life. The mean scores of both groups and the standard deviations are shown in table 7.6.

TABLE 7.6. Mean scores of the brain injured group and the significant other's ratings of domain-specific life satisfaction.

	HI person N = 39		**Carer N = 39**		
	Mean	s.d.	Mean	s.d.	
Satisfaction with... (0-6)					
Aims	3.81	1.48	2.97	1.46	*
Care	4.84	1.22	5.11	.91	
Spending days	3.97	1.27	3.59	1.26	
Family life	4.69	1.38	4.37	1.32	
Financial situation	3.84	1.62	3.26	1.64	
Friendships	3.95	1.61	3.92	1.48	
Independence	4.14	1.62	4.06	1.60	
Leisure	3.86	1.55	3.62	1.41	
Mental abilities	3.89	1.48	3.92	1.38	
No Partner	2.00	1.25	2.06	1.28	
Relationship with partner	4.69	1.31	4.92	1.34	
Physical abilities	4.26	1.59	3.55	1.60	
Religious life	4.75	.75	4.45	.78	
Sexual life	3.13	1.66	3.00	1.67	
Work situation	3.61	1.67	3.42	1.52	
Yourself	3.80	1.55	3.53	1.40	
Life	3.97	1.62	3.44	1.42	

* indicates a significant difference at $p < .01$ level

A Bonferroni test for multiple comparisons was used for the comparison in terms of domain-specific life satisfaction in order to avoid making a type I mistake. The significant p-level was therefore .05/16 = .003.

When compared using the Mann-Whitney test, no differences were found between satisfaction ratings of the brain injured person and the carer which passed the Bonferroni test.

Overall, it would seem that brain injured people and their significant others agree highly in terms of the brain injured person's satisfaction with life domains. This is a significant finding because it strengthens the *reliability* of the ratings of the brain injured group of their own subjective situation.

7.5. NEURO-BEHAVIOURAL PROBLEMS

Several neuro-behavioural problems were frequently reported in the present investigation by the brain injured people and their carers (table 7.7.). These are often found in other studies as well and are central to the clinical picture after traumatic brain injury (section 1.6). They include: cognitive problems related to slowness, memory problems, and concentration; And personality/emotional problems related to frustration, anger/irritation, and loneliness.

Kreutzer, Seel, and Harwitz (1996) published norms for the NFI. Table 7.8. shows percentile scores for the 6 sub-scales of the NFI when compared to a sample of brain injured patients (men and women), aged between 25 and 34 who have been unconscious for more than 14 days. Kreutzer et al. (1996) did not give any information on the number of people used to obtain these standardised scores.

Compared to Kreutzer's norm sample, the brain injured sample in the current study scored high on aggression. The brain injured sample's ratings of aggression fell in the 69th percentile, and the carer's rating of aggression fell in the 76th percentile. The present sample had relatively few motor problems (carer, 34th percentile; brain injured person 38th percentile). The other sub-scales were all around the 50th percentile of the standardised population.

Table 7.7. Highest rated neuro-behavioural problems (on a scale from 1 to 5) by the brain injured person and the carer.

Brain injured person N = 48		**Significant other N = 39**	
Forget people's names	3.06	Writes slowly	3.50
Frustrated	3.00	Reads slowly	3.34
Difficulty thinking of the right word	2.87	Frustrated	3.26
Easily distracted	2.87	Easily angered/irritated	3.23
Make spelling mistakes	2.81	Concentration is poor	3.23
Read slowly	2.80	Misplaces things	3.15
Forget phone numbers	2.77	Lonely	3.08
Bored	2.72	Forgets phone numbers	3.05
Forget if you have done things	2.71	Argues	3.05
Write slowly	2.67	Easily distracted	3.05
Misplace things	2.64	Can't get mind off certain thoughts	3.03
Difficulty making conversation	2.63	Tires easily during physical activity	3.03
Lonely	2.63	Forgets if he has done things	3.00
Easily angered/irritated	2.62	looses train of thought	2.97
Concentration is poor	2.62	Restless	2.95

All in all, carers seemed to report more neuro-behavioural problems than the brain injured person. Paired-samples t-test compared the problems reported by the brain injured with those reported by the carers (table 7.8.). Significant others reported significantly more memory/attention problems and depression. A comparison of ratings of aggression, communication, and motor problems almost reached significance.

Table 7.8. Pairwise Comparison between the brain injured sample and their significant others on the Neuro-behavioural Functioning Inventory scales and standardised percentile scores on the NFI-R

	Brain injured			Significant other				
	pairs	Mean	s.d.	percentile	Mean	s.d.	percentile	t	p
Aggression	39	18.79	6.1	69	20.9	7.8	76	-1.97	.056
Attention/Memory	39	44.38	14.7	54	49.90	14.2	66	-2.32	.026 *
Communication	39	24.69	6.4	50	26.95	7.4	62	-1.99	.054
Depression	39	31.62	10.7	54	34.95	11.6	69	-2.09	.044 *
Somatic	39	18.21	5.4	46	19.33	6.2	54	-1.32	.195
Motor	39	15.74	5.1	38	17.51	6.6	34	-1.97	.056

* Indicates a significant difference

7.6. CONCLUSIONS

A number of conclusions can be drawn from this chapter:

- Brain injured people are particularly dissatisfied about 'not having a partner' and their sexual life. They are most satisfied about their ability to take care of themselves

- There was no difference between the brain injured group and the control group in terms of their ratings of global satisfaction

- Brain injured people rated themselves less satisfied with two specific domains in their life than the controls: their mental abilities, and their sexual life;

- There was no difference between the brain injured group and the control group in terms of their ratings of what they find important in life

- Brain injured people were significantly less optimistic about the future in some of the domains in life than the control group. They were, however, equally hopeful about the future.

- Brain injured people and their significant agreed in terms of their ratings of the brain injured person's domain-specific satisfaction. The similarity in their ratings strengthens the trust in the validity and reliability of the self-reports of their subjective status by the brain injured group

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CHAPTER EIGHT The Relationship between Injury-related Variables and Subjective Outcome

8.1. INTRODUCTION

One of the central questions of this thesis concerns the relationship between injury-related variables on the one hand, and subjective quality of life on the other hand (Chapter Five).
This chapter will explore the relationship between subjective outcome and adjustment on the one hand, and objective and 'perceived objective' factors on the other hand. The order of the sections roughly follows the WHO classification of disease and illness, from pathology to handicap. Following the discussion in section 4.7., the relationship between symptoms and subjective outcome and the relationship between subjective outcome and self-perceived health will also be investigated.

The relationship between the duration of post traumatic amnesia and subjective outcome and adjustment will be described in section 8.2.
Post traumatic amnesia has been shown to be related to lesions in hemispheric areas of the brain, but also to lesions in more central areas of the brain (Wilson, Teasdale, Hadley, Wiedmann, and Lang, 1993). That is why the severity of the injury (as measured by the length of the post traumatic amnesia) can be set at the level of pathology in the WHO model of disease and the consequences of disease.

Neuro-behavioural problems, rated by the carer, are often seen as a more objective way of obtaining information on the brain injured person than his/her own ratings. The information obtained this way is at the level of impairments/disabilities in the WHO model. It is not possible

to state clearly whether the Neuro-behavioural Functioning Inventory is mainly concerned with impairments or disabilities. Some items require direct ratings of functions (concentration, seizures, balance), whereas others tap more into the everyday effects of loss of functions ('forget what you read', 'trouble understanding conversation'). The relationship between carer-perceived neuro-behavioural problems and subjective outcome will be discussed in section 8.4.
Self-perceived health is represented in terms of self-ratings of neuro-behavioural problems. This will be discussed in section 8.5.

The literature reviewed in section 4.7. suggested that the further one progresses from pathology, to disabilities, to handicaps, to self-perceived health, the greater the relationship with subjective quality of life. This hypothesis will be tested in this chapter. It is expected that through the progression from severity of the traumatic brain injury, to impairments, to carer-perceived neurobehavioural problems, to patient-perceived neurobehavioural problems, the relationship with subjective quality of life will become stronger.

8.2. THE RELATIONSHIP BETWEEN POST-TRAUMATIC AMNESIA AND SUBJECTIVE OUTCOME AND ADJUSTMENT

8.2.1. Procedure

Data on post traumatic amnesia were collected in the way described in section 5.5.2.1. If a reliable estimate of post traumatic amnesia was not available or if the researcher was unable to ascertain it retrospectively with certainty, then no post traumatic amnesia was recorded for that particular brain injured person. Data on post traumatic amnesia was available for 42 brain injured people.

8.2.2. Results

8.2.2.1. THE RELATIONSHIP BETWEEN LEVEL OF SATISFACTION AND DURATION OF PTA

Figures 8.1. and 8.2. show the relationship between the duration of post traumatic amnesia and global evaluations of satisfaction with life. They show that there is no relationship between the two. This was confirmed by the weakness of the Pearson correlation between post traumatic amnesia and the Satisfaction with Life Scale (r = .11, not significant) and between post traumatic amnesia and the answer to the question "*How do you feel about your life*"? (r = .02; not significant). Table 8.1. shows the Pearson correlations between PTA on the one hand, and the Satisfaction with Life Scale, and answers given to the question "*How do you feel about your life?*".

TABLE 8.1. Pearson correlations between ratings of global life satisfaction and Post traumatic amnesia (one-tailed); N = 42

	r	p
Satisfaction with Life Scale Score (0-35)	.11	ns
"How do you feel about your life?"[1] (0-6)	.02	ns

(a) ns not significant;

[1] This is a Spearman correlation

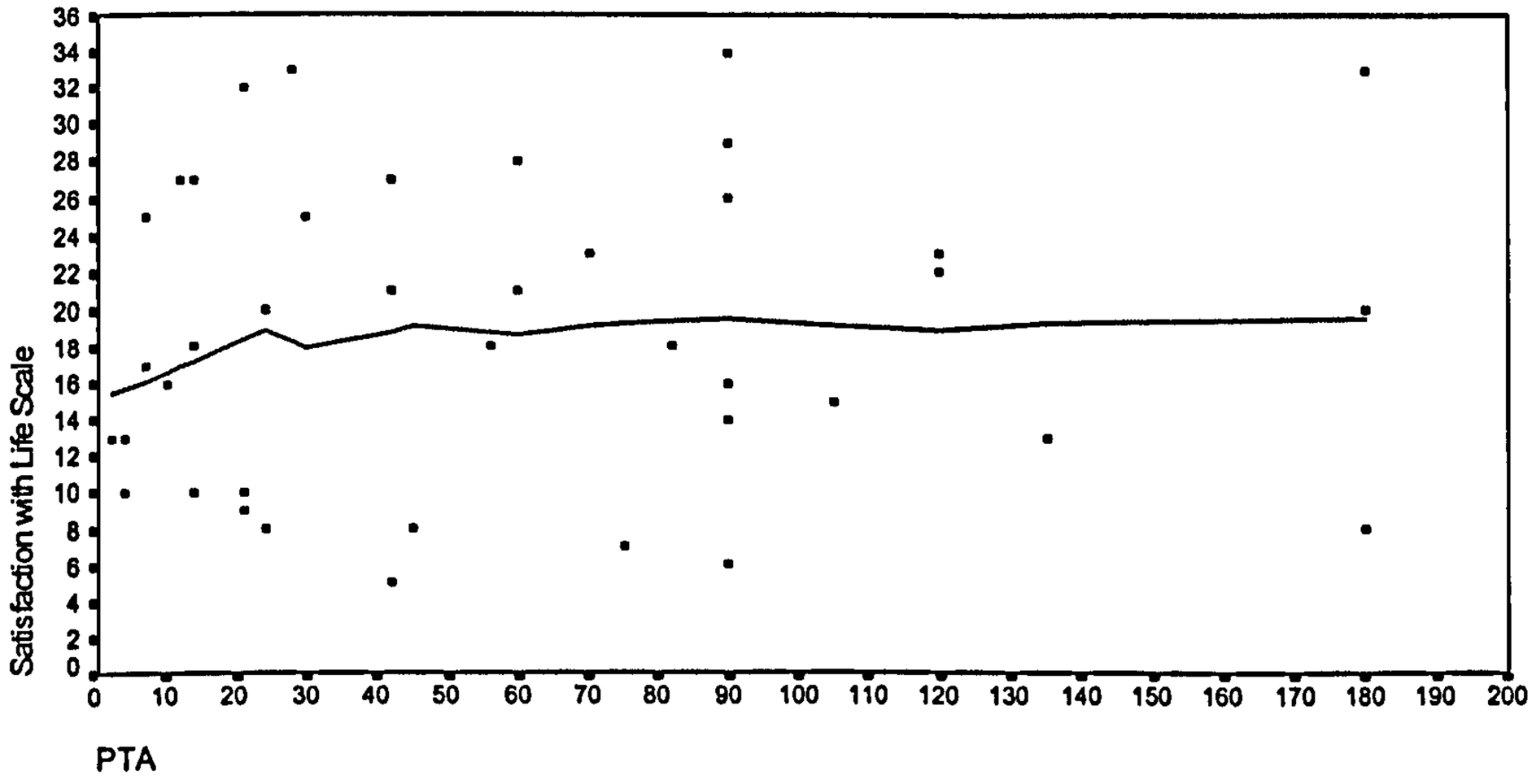

FIGURE 8.1. A scatterplot of the relationship between PTA and The Satisfaction With Life Scale total score. The Lowess plot fits 50% of the points.

Overall, it can be concluded that there was no relationship between duration of post traumatic amnesia and the brain injured person's ratings of satisfaction.

8.2.2.2. The Relationship between the Duration of PTA and Other Measures of Adjustment

Pearson correlations showed that there was no linear relationship between the duration of post traumatic amnesia and self-esteem (r = -.07), and modest, but insignificant linear relationships between the duration of post traumatic amnesia and acceptance of limitations (r = -.19), HAD-depression (r = -.18), and HAD-anxiety (r = -.20) (Table 8.2.).

TABLE 8.2. Pearson correlations between the duration of post-traumatic amnesia and four measures of adjustment (one-tailed).

Measure of adjustment		r	p
Self-esteem	N = 41	-.07	ns
Acceptance of limitations	N = 38	-.19	ns
Anxiety	N = 40	-.20	ns
Depression	N = 40	-.18	ns

(a) ns not significant

The results suggest that there was no clear significant relationship between the duration of post traumatic amnesia and measures of depression, anxiety, self-esteem and acceptance.

8.3. THE RELATIONSHIP BETWEEN CARER-PERCEIVED NEURO-BEHAVIOURAL PROBLEMS AND PATIENT-PERCEIVED SUBJECTIVE OUTCOME

8.3.1. Introduction

The significant other's ratings of the brain injured person's neuro-behavioural problems are often seen as more reliable than those of the brain injured person himself (Fleming et al., 1996). In this section, neuro-behavioural problems, as perceived by the carer, will be related to measures of subjective outcome and adjustment (as perceived by the brain injured person).

Thirty nine significant others filled in the Neuro-behavioural Functioning Inventory.

8.3.2. Results

8.3.2.1. THE RELATIONSHIP BETWEEN PATIENT-PERCEIVED LEVEL OF SATISFACTION AND CARER-PERCEIVED NEUROBEHAVIOURAL PROBLEMS

Table 8.3. shows Pearson correlations between ratings of satisfaction and other measures of adjustment on the one hand and neuro-behavioural problems as perceived by the carer on the other hand.

Table 8.3. shows that the higher the total carer-perceived neurobehavioural problems score, the lower the brain injured person's rating of his own global satisfaction ($r = -.33$; $p < .05$). The total neurobehavioural score was also significantly related to level of anxiety ($r = .34$; $p < .05$), depression ($r = .43$; $p < .05$), acceptance ($r = -.60$; $p < .001$) and self-esteem ($r = -.42$; $p < .01$.

TABLE 8.3. Pearson correlations between neuro-behavioural problems, as perceived the carer, and ratings of satisfaction and other measures of adjustment (one-tailed)

	Total Neurobehavioural Score N = 39
Satisfaction with Life Scale	-.33 *
Anxiety	.34 *
Depression	.43 * *
Acceptance	-.60 * * *
Self-esteem	-.42 * *

(a) * Represents a significant correlation at $p < .05$
(b) * * Represents a significant correlation at $p < .01$
(c) * * * Represents a significant correlation at $p < .001$

Neurobehavioural problems, as perceived by the carer were therefore significantly related to the brain injured person's ratings of subjective outcome.

8.3.2.2. The Relationship between Carer-perceived Neurobehavioural Problems and Other Measures of Adjustment

Table 8.3. shows the Pearson correlations between neuro-behavioural problems as perceived by the carer, and four measures of adjustment: self-esteem, acceptance of limitations, anxiety, and depression.

The total neurobehavioural score was significantly correlated with depression ($r = .43$; $p < .01$), acceptance ($r = -.60$; $p < .001$), and self-esteem ($r = -.42$; $p < .01$). This indicates that the more carer-perceived neurobehavioural problems the brain injured person suffered from, the less adjusted he was likely to be.

8.3.2.3. Summary of the Results

Carer-perceived neurobehavioural problems were significantly correlated with measures of global satisfaction.

Carer-perceived neurobehavioural problems appeared to much more clearly significantly correlated with other measures of adjustment.

8.4. THE RELATIONSHIP BETWEEN SELF-PERCEIVED NEURO-BEHAVIOURAL PROBLEMS AND SUBJECTIVE OUTCOME

8.4.1. Introduction

This section will look at the relationship between carer-perceived neurobehavioural problems and subjective outcome (as perceived by the brain injured person). 48 NFI questionnaires were used for the analysis.

8.4.2. Results

8.4.2.1. THE RELATIONSHIP BETWEEN LEVEL OF SATISFACTION AND SELF-PERCEIVED NEUROBEHAVIOURAL PROBLEMS

Table 8.4. shows Pearson correlations between measures of global satisfaction and neuro-behavioural problems as perceived by the brain injured person.

The total self-perceived neurobehavioural problems score was highly correlated with ratings of the satisfaction with Life Scale ($r = -.55$; $p < .001$). This indicates that the more neurobehavioural problems brain injured people *think* they suffer from, the lower their ratings of their own level of satisfaction.

It may be argued that awareness of limitations influences the relationship between self-perceived neurobehavioural problems and subjective quality of life. A partial correlation was therefore carried out between self-perceived neurobehavioural problems and the Satisfaction with Life Scale, controlling for the influence of 'awareness'. This partial correlation was -.49 ($p < .001$). It would therefore seem that the relationship between self-perceived neurobehavioural problems and global satisfaction is high, irrespective of the influence of 'awareness'.

TABLE 8.4. Pearson correlations between neuro-behavioural problems, as perceived the brain injured person, and ratings of satisfaction and other measures of adjustment (one-tailed)

	Total Neurobehavioural Score N = 48
Satisfaction with Life Scale	-.55 * * *
Anxiety	.57 * * *
Depression	.67 * * *
Acceptance	-.66 * * *
Self-esteem	-.62 * * *

* * Represents a significant correlation at $p < .01$
* * * Represents a significant correlation at $p < .001$

8.4.2.2. The Relationship between Self-perceived Neurobehavioural Problems and Other Measures of Adjustment

Table 8.4. shows the Pearson correlations between neuro-behavioural problems as perceived by the brain injured person and four measures of adjustment: self-esteem, acceptance of limitations, anxiety, and depression.

The total self-perceived neurobehavioural problems score was highly significantly related with anxiety ($r = .57$; $p < .001$), depression ($r = .67$; $p < .001$), acceptance of limitations (r - -.66; $p < .001$), and self-esteem ($r = -.62$; $p < .001$). This means that the more neurobehavioural problems the brain injured person *thinks* he has, the less well adjusted he is.

8.4.2.3. Summary of the Results

Self-perceived neurobehavioural problems were highly significantly correlated with the brain injured person's own ratings of his levels of satisfaction and four other measures of adjustment (anxiety, depression, acceptance of limitations, and self-esteem).

8.5. THE RELATIONSHIP BETWEEN PTA, CARER-PERCEIVED NEUROBEHAVIOURAL PROBLEMS, SELF-PERCEIVED NEUROBEHAVIOURAL PROBLEMS AND SUBJECTIVE QUALITY OF LIFE AND ADJUSTMENT

This chapter has looked at the relationship between injury-related variables (including post traumatic amnesia, carer-perceived neurobehavioural problems and self-perceived neurobehavioural problems) and ratings of satisfaction and other measures of adjustment. This section will particularly investigate whether any injury-related variable is particularly more related to subjective quality of life.

Table 8.5. The Pearson Correlations between injury-related variables and Subjective Quality of Life.

		r	p
Post traumatic amnesia	N = 41	.11	ns
Total carer-perceived neurobehavioural problems	N = 38	-.33	< .05
Total self-perceived neurobehavioural problems	N = 46	-.55	< .001

Table 8.5. shows the correlation between post traumatic amnesia, carer-perceived neurobehavioural problems and self-perceived neurobehavioural problems on the one hand, and subjective quality of life (as measured by the satisfaction with Life Scale) on the other hand.

Table 8.5. shows that, as predicted in the first section of this chapter, there does seem to be a steady progression from post traumatic amnesia to self-perceived neurobehavioural problems in terms of their correlations with subjective quality of life. The next question is whether the difference between these correlations is significant.

Hotelling's t test[1] can determine whether differences between the correlations between a and b with c are significant. This test can be used when "*we have correlated two predictor-test variables with the same criterion of successful behavior of some kind*" (Guilford, 1965; pp. 190). In order to determine whether patient-perceived problems are genuinely superior in predicting subjective quality of life, difference in correlations was significant, Hotelling's t was used.

Hotelling's t for the significance of the difference between the correlations of self-perceived and carer-perceived neurobehavioural problems with subjective quality of life has a value of 2.28. If the .05 level is adopted, and a one-tail test (because the alternative hypothesis is that the higher correlation represents a genuinely higher correlation than the lower one), the t needed is 1.68 (from the normal curve table). The null-hypothesis is therefore rejected, and the correlation between self-perceived neurobehavioural problems and subjective quality of life is significantly higher than the correlation between carer-perceived neurobehavioural problems and subjective quality of life.

Hotelling's t for the significance of the difference between the correlations of self-perceived neurobehavioural problems and post-traumatic amnesia with subjective quality of life has a value of 3.42. If the .05 level is adopted, and a one-tail test (because the alternative hypothesis is that the higher correlation represents a genuinely higher correlation than the lower one), the t needed is 1.69 (from the normal curve table). The null-hypothesis is therefore rejected, and the correlation between self-perceived neurobehavioural problems and subjective quality of life is significantly higher than the correlation between post-traumatic amnesia and subjective quality of life.

It was therefore also found –as expected- that self-perceived neurobehavioural problems are significantly more related to subjective quality of life than post traumatic amnesia as well.

Hotelling's t for the significance of the difference between the correlations of carer-perceived neurobehavioural problems and post traumatic amnesia and subjective quality of life has a value of 1.66. If the .05 level is adopted, and a one-tail test, the t needed is 1.69. The null-hypothesis is therefore accepted, and the correlation between carer-perceived neurobehavioural problems and

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[1] [1] Hotelling's t can be calculated as follows (Guilford, 1965): $t = (r12 - r13) * (\sqrt{((N-3)(1+r23)/(2(1 - r^2 23 - r^2 12 - r^2 13 + 2r23r12r13)))}$ in which r stand for a correlation; 1 refers to the outcome variable, 2 and 3 to the predictor variables.

subjective quality of life is not significantly higher than the correlation between post traumatic amnesia and subjective quality of life.

It would therefore seem that self-perceived neurobehavioural problems are significantly higher correlated with subjective quality of life than carer-perceived neurobehavioural problems, and post traumatic amnesia.

The separate status of self-perceived neurobehavioural problems within the injury-related variables was confirmed by data shown in appendix 8.1.
Self-perceived neurobehavioural problems was not significantly correlated with post traumatic amnesia ($r = 0.18$; $p = .125$). In sharp contrast with these results, it was found that carer-perceived neurobehavioural problems were significantly related to post traumatic amnesia ($r = .35$; $p = .02$).

These results indicate that the brain injured person's perception of his own problems is not related to the actual severity of the accident. Such a relationship does exist, however between carer-perceived problems and objective injury-related variables. These results suggest that the carer's ratings of the brain injured person's problems is actually related to the presence of actual problems, whereas the extent of the brain injured person's own assessment of his own problems is not necessarily related to the actual presence of problems as a direct result of the traumatic brain injury.

Overall, it would seem that the correlation between self-perceived neurobehavioural problems and subjective quality of life on the on hand and the correlation between carer-perceived neurobehavioural problems, and post traumatic amnesia and subjective quality of life were significantly different. This implies that self-perceived problems is a better predictor of subjective quality of life than carer-perceived problems, or the objective measure of injury-related problems (post traumatic amnesia).

Self-perceived problems was also superior to more objective measures of problems in terms of its correlation with other measures of adjustment as well. Table 8.6. shows the Pearson correlations between all four injury-related variables and four measures of adjustment. It is clear (and confirmed

by Hotelling's t) that in all cases self-perceived neurobehavioural problems are significantly higher correlated to all four measures of adjustment than post traumatic amnesia.

Table 8.6. The Pearson Correlations between injury-related variables and other measures of adjustment (N between brackets)

	Anxiety	Depression	Acceptance	Self-esteem
Post traumatic amnesia	-.20 (40)	-.18 (40)	-.20 (38)	-.08 (41)
Neurobehavioural problems – Carer	.34 * (38)	.43 * * (38)	-.60 * * * (35)	-.42 * * (37)
Neurobehavioural problems - Patient	.57 * * * (45)	.67 * * * (45)	-.66 * * * (43)	-.62 * * * (46)

* P < .05; * * p < .01; * * * p < .001

8.6. CONCLUSIONS

A number of conclusions can be drawn from this chapter:

- Post traumatic amnesia was not related to brain injured participant's ratings of satisfaction or other measures of adjustment

- The total neurobehavioural score, as perceived by the carers, was significantly related to global satisfaction; Carer-perceived neurobehavioural problems were significantly correlated with other measures of adjustment, particularly with 'acceptance of limitations'.

- Self-perceived neurobehavioural problems were highly significantly correlated with ratings of satisfaction, and other measures of adjustment;

- The carer's ratings of the brain injured person's problems is related to the presence of actual problems, whereas the extent of the brain injured person's own assessment of his own problems is not necessarily related to the actual presence of problems as a direct result of the traumatic brain injury.

- The main conclusion of this chapter is that self-perceived neurobehavioural problems were significantly more highly associated with subjective quality of life than carer-perceived neurobehavioural problems, or post traumatic amnesia.

CHAPTER NINE The Relationship between Adaptive Tasks and Subjective Outcome

9.1. INTRODUCTION

Chapter 8 has shown that the relationship between objective, injury-related variables on the one hand and subjective outcome and adjustment on the other hand was relatively weak. This was to be expected, given the lack of success in finding a significant relationship between these variables in normal and clinical populations (Argyle, 1987, Diener, 1984; 1993; Diener et al., 1999). The same authors have pointed out that the relationship between more personal and subjective variables (such as personality, self-esteem, or acceptance of self) and subjective outcome is much stronger.

In Chapter Three, a number of adaptive tasks were identified that the brain injured person needs to deal with after a traumatic brain injury. In the current chapter, the relationship between these tasks and subjective outcome will be investigated in the sample of severely brain injured people. More specifically, it was postulated in Chapter Five that the brain injured person's level of adjustment would be positively related to subjective outcome, with better adjustment being related to superior subjective quality of life than worse adjustment.

As described in chapter three, stage models of adjustment were the main theoretical framework chosen in this thesis with regard to adjustment. The rationale is briefly described again below:

Firstly, it was decided not to focus on coping, since this had been done before (e.g. Kendall and Terry, 1996; Moore and Stambrook, 1992) and was therefore not identified as a 'gap' in the literature. Furthermore, the researcher felt that coping mechanisms may contribute towards adjustment, but that the adjustment process itself consists of different mechanisms.

The second step was a decision to focus on stage models of adaptation given its relatively long history (since Kubler-Ross, 1969) focusing on adjustment to 'loss', i.e. adjustment to chronic conditions or adjustment to the loss of a loved one. There is much literature and research in this area which has never been applied to the field of head injury.

The main thrust of almost all stage models of adaptation (10 stage models adjustment put forward by different authors are shown in section 3.3.2) is that, after loss of any kind, people need to give up old perceptions from before the loss occurred and integrate a new reality into their perception of self and the world. Necessarily, people need to know what they have lost before they can integrate it ('awareness').

The model of adjustment adopted in this project is therefore an amalgam of the features in the models described in section 3.3.2.

People who have experienced loss first need to realise what the consequences of this loss are for their daily life (becoming aware). They subsequently need to incorporate these changes into their perception of self so that they no longer diminish their perception of self, but has become part of it ('acceptance of limitations'). They can then stop thinking about the past, and start looking forward towards the re-organisation of their life

The adaptive tasks have been operationalised in the present project in order to relate them to subjective outcome and adjustment. First, the relationship between the brain injured person's level of awareness and subjective quality of life (section 9.2.), then between his level of acceptance and subjective quality of life (section 9.3.), and finally the relationship between his past–future orientation and subjective quality of life (section 9.4.) will be reported.

It was expected that people who have more awareness, have accepted their limitations, and who look towards the future have a higher quality of life than people who do not do so (see research questions in Chapter Five).

9.2. THE RELATIONSHIP BETWEEN AWARENESS OF LIMITATIONS AND SUBJECTIVE OUTCOME

9.2.1. Procedure

Prigatano, Altman, and O'Brien (1991) suggested three ways of scoring awareness.
The first was to subtract the average competency score of the patient from the average competency score of the carer.
The second was to compute the number of items in which the carer's rating is greater than the patient's rating.
And the third method was to consider the actual difference in scores between patient and carer on each item and then to add the differences up across items to obtain an overall '(un)awareness score'.
The third method was chosen for the current study because it takes the absolute differences between the ratings of the significant other and the brain injured person on individual items into account. However, a possible disadvantage of this approach is that it is possible to have a negative 'awareness score', indicating that the patient perceives more problems than the carer.

In order to obtain measures of awareness, the brain injured person's own ratings of himself on the Neuro-behavioural Functioning Inventory and on the Brooks Personality Ratings Scale were subtracted from the ratings of the significant other. The idea underlying this method of getting an 'awareness score' is that the brain injured person's report of his own condition are likely to be distorted or inaccurate, and that a close observer will be able to give a more accurate picture (Fleming, Strong, and Ashton, 1996). By subtracting the brain injured person's perception of his problems from that of the significant other, one obtains an indication of the extent to which the brain injured person's perception of his problems differs from that of his significant other. It is of course possible for carers to perceive fewer problems than the patients (and this happened a number of times in this research study. However, it has been frequently used in other studies, is one of the few available measures, and is used in conjunction with more qualitative measures

of awareness in this study. This difference in perception of problems is used as a marker of awareness of limitations.

The 'Depression' sub scale of the NFI was excluded from the calculation of the 'awareness score' since depression is not necessarily a 'neurobehavioural' problem. Items on the Brooks Personality Scale were scored in such a way that the negative adjective had the highest score (similar to the NFI). Two items were left out of the calculation of the 'awareness score'. 'talkative - quiet' because neither is necessarily positive or negative, and 'happy - unhappy' because personal ratings of happiness are used in this study as outcome variables and can therefore not be part of one of the predictor variables.

An awareness-percentage score was then calculated by dividing the difference in scores between patients and carers by the theoretically possible difference between them, and multiplied by 100. The scores for all six areas were then added up to obtain an overall 'awareness' score. This score represented the percentage to which brain injured people were thought to under- or overestimate their own problems compared to their significant others. The higher the 'awareness score', the less aware the brain injured patient was of his own problems. This measure will be referred to in the rest of the chapter as the 'awareness score'. Eleven out of the total 36 awareness scores were negative, indicating that the patient actually perceived more problems than the carer. 25 out of the total 36 awareness scores were positive, indicating that the carer perceived more neurobehavioural problems than the patient.

9.2.2. Results

9.2.2.1. COMPARISON BETWEEN BRAIN INJURED PEOPLE AND THEIR CARERS

Paired samples t-tests (one-tailed) were carried out to find out whether there any differences between brain injured people and their carers in terms of neuro-behavioural problems. Overall, it was found that brain injured people tended to underestimate their own neuro-behavioural problems. Table 9.1. shows the means of the ratings of the brain injured group and their carers in terms of the patient's neurobehavioural problems.

Table 9.1. Means and standard deviations of the brain injured group and their significant others on domains of the Neurobehavioural Functioning Inventory

	Brain injured Person N = 39		Significant Other N = 39		
	M	s.d.	M	s.d.	
Somatic	18.71	6.2	19.33	6.2	
Motor	15.97	5.6	17.51	6.6	
Memory/attention	44.44	15.1	49.90	14.2	*
Communication	24.60	6.9	26.95	7.4	*
Aggression	18.04	6.0	20.92	7.8	*

* Indicates a significant difference

Carers rated brain injured people as more aggressive [$t = -2.29$, $df = 36$, $p < .05$], having more communication problems [$t = -2.03$, $df = 36$, $p < .05$], and as having more memory/attention problems [$t = -2.21$, $df = 36$, $p < .05$]. No significant differences were found between patients' and carers' ratings of motor problems [$t = -1.95$, $df = 36$] or somatic problems [$t = -1.19$, $df = 36$, $p < .05$]. When all items of the NFI were added up and compared between the brain injured and the carer groups, it was found that brain injured people significantly underestimated their neurobehavioural problems compared to the significant others [$t = -2.54$; $df = 38$; $p < .01$].

9.2.2.2. The Relationship between Awareness and Ratings of Satisfaction and Adjustment

Table 9.2. shows the correlations between the awareness scores and ratings of satisfaction. The higher the 'awareness score', the less aware the brain injured patient is of deficits in a particular domain.

The relationship between the Satisfaction with Life Scale and the awareness score was not significant (r = .16; p = .18).

Table 9.2. Pearson Correlations between level of awareness of deficits and subjective outcome and adjustment (one-tailed)

	Awareness Score	
	N = 36	
	R	p
SWLS	.15	.ns
Anxiety	-.05	ns
Depression	-.22	ns
Acceptance	.02	ns
Self-esteem	.17	ns

Table 9.2. shows the Pearson correlations between the awareness score and four measures of adjustment: self-esteem, acceptance of limitations, anxiety, and depression. Level of awareness was not significantly correlated with any of these measures of adjustment.

Overall, it can be concluded that level of awareness limitations does not seem to be significantly correlated with ratings of satisfaction and measures of adjustment.

9.2.3. Qualitative Analysis of the Relationship between Awareness and Subjective Quality of Life

The previous section showed that no relationship was found between the brain injured person's level of awareness on the one hand and subjective outcome and adjustment on the other hand.

In this section, an attempt will be made to shed light on this result by describing four case studies, each with a different level of awareness and subjective well-being.

9.2.3.1 BECOMING AWARE OF THE CONSEQUENCES OF TRAUMATIC BRAIN INJURY

Despite the fact that no clear evidence was found for a relationship between level of awareness and subjective outcome *at the moment of assessment*, there were clear indications from the qualitative interviews that becoming aware of the consequences of a traumatic brain injury does in many cases initially lead to increased levels of depression and anxiety. This is an observation that has been made before in the literature (e.g. Lezak and O'Brien, 1988).

Many significant others (and some brain injured people) made a direct link between the time the person started to realise how the traumatic brain injury had affected him and immediate maladjustment.

The mother of patient 011 said, when asked what happened when he started to realise what the consequences of his traumatic brain injury were: "*he felt useless...worthless...no good to anybody...quite suicidal at one stage*". The mother of patient 008 –who is a typical 'frontal' patient: impulsive, distractible, irritable- said that her son is not always aware of the consequences: "*it's like in waves...there are times when he is very lucid, and he does realise then, and that is when he gets very down*".

The parents of patient 015 described the anxiety their son experienced when he realised that he could not cope with the same pressures and workload at work as before the accident: "*Once he started to become a bit aware...he was always holding someone's hand...and...prior, he never showed any emotion...he was just a frightened little boy...and he said: 'There is this great big hole...in the middle of my head and there is a plate and it has moved and I cannot get it back'...he was really frightened as to what he was thinking, what he was feeling*".

Brain injured people also described similar experiences.

Patient 010 said: "*...first understanding that I had been in an accident...I first thought it was a dream...then the depression when I got home...*".
And patient 013 talks about the way he found out he was no longer the same person and what effect it had on him: "*Things I did at work. Just what I would say to be easy things I found difficult...I felt there wasn't a problem, I was the same as I was, but obviously I was not...I shied away and tried to go again...I used to get depressed...*".

One interview (with 016) was cut short because he became very tearful when describing the consequences of his traumatic brain injury. His mother later explained that, three years post-injury, he was becoming aware of what he is *not* capable of. The leader of the local Headway group later confirmed that 016 was indeed going through a process of gradually becoming aware of the consequences of his fall from a van.

These stories clearly indicate that in these cases, becoming aware of the changes following his traumatic brain injury led to a simultaneous increase in distress.

9.2.2.2. Four possible relationships between awareness and happiness

The relationship between lack of awareness and subjective outcome and adjustment is not straightforward. This is shown schematically in figure 9.1.

Happiness without Awareness	Happiness with Awareness
Unhappiness without Awareness	Unhappiness with Awareness

Figure 9.1. Four possible relationships between happiness and Awareness of limitations

Theoretically, four possible combinations are:

1. Happiness without awareness
2. Happiness with awareness
3. Unhappiness without awareness
4. Unhappiness with awareness

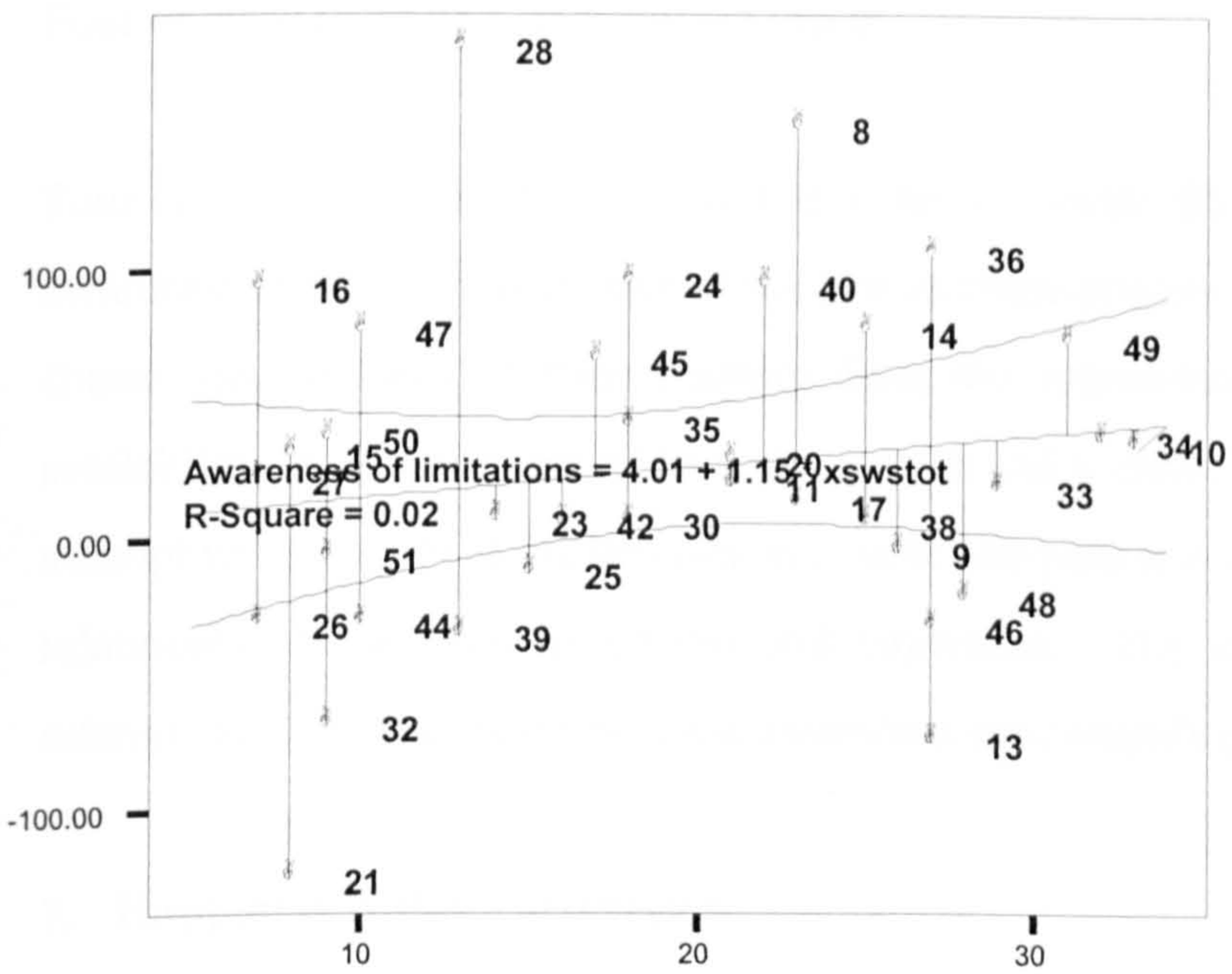


Figure 9.2. Regression Plot of the Relationship between level of awareness and scores on the Satisfaction with Life Scale for every brain injured person

The fact that no consistent statistical relationships were found between awareness and happiness suggests that the brain injured sample was distributed over these four positions. This can also be observed from the scatterplot in figure 9.2. This plot shows, for every brain injured person, the relationship between level of unawareness on the one hand, and scores on the Satisfaction with Life Scale on the other hand. It also shows the linear regression line, and both 95% confidence interval lines. Finally, it shows the distance away from the regression line for each brain injured person. This way, it can be established whether the person is an 'outlier' who does not conform to the usual pattern.

It is not possible to calculate the number of people who fit into each cell in figure 9.1. unless one draws two relatively random lines. The main reason is that there is no golden standard as to where 'aware', 'unaware', 'happy', and 'unhappy' begin and end exactly. The main measure of awareness used (the awareness score) and the main measure of subjective quality of life used were both at interval level, and therefore difficult to separate into 'aware' and 'unaware' or 'happy' and 'unhappy'. However, a number of brain injured individuals were clearly at the extreme ends of each measure (see appendix 9.2.), and could therefore easily be classified as 'aware' or 'happy'. Four of these cases will be discussed below.

Four case studies will be discussed in order to clarify the nature of the relationship between awareness and happiness in each of the four extreme positions described above. These cases were chosen on the basis of their distance from the regression lines (as far as possible) and the availability of an interview of both the patient and a carer. In the description of each case, no attempt will be made to explain *why* this particular person is happy or unhappy and what the exact relationship is between awareness and happiness. The cases simply illustrate that different relationships between happiness and awareness are certainly possible.

1. Happiness without awareness

Patient number:	045
Age:	28 years and 6 months
Nature of Accident:	Passenger in car accident
Time post-injury:	5 years
PTA:	21 Days
Cognitive Deficits:	"Permanent loss of the temporal half of the visual field in both the left and right eye"; "Verbal working memory and spatial long-term memory are impaired". His problems with planning and organisation are "associated with frontal lobe damage". (From neuropsychological report)
Work:	Part-time Lab technician, working with animals
Marital Status:	Divorced with 2 children; Lives with his parents

045 scored in the upper third of the client sample in terms of unawareness, i.e. his mother thought he was markedly more impaired than he did.

When asked what the consequences of his traumatic brain injury have been, he responded: "*I've had my driver's licence taken away...and my double vision...I am actually a much better person...because before I was a bit violent...but now it's sort of calmed me down*". He thinks his "*memory seems to be fine*" and has "*no problem at all*" organising and planning things. He does acknowledge being impulsive and the fact that he would not be able to live on his own "*because I can't cook*".

His mother described his problems with his short-term memory, impulsivity, inability to do two things at once, and slowness "*in grasping things*". She said "*I don't think he realises*" when asked if he is always aware of the way he has changed since the accident. When asked if he realises that his memory is not what it used to be, she says: "*No, I don't think so. He would say: 'I am not stupid' – his favourite word...He thinks he is totally okay…*".

Overall, 045 knew he had a traumatic brain injury, realised some of the consequences (particularly the ones he could not deny, such as the visual field loss), but did not seem to realise the more subtle mental effects of the traumatic brain injury.

045 rated himself 'satisfied' or higher on all the 16 domains of the domain-specific life satisfaction scale. He said he was "*happy at the moment...I'm getting in the shape I've always wanted...I'm very happy with the girl I have just met…*". His mother thought he was very happy with his two daughters, and "*he and his ex-wife are very much on friendly terms*". He was happy with the work he was doing, and had recently met a girl he liked.

To summarise, 045 did not seem to be aware of the subtle, negative changes that have taken place. But they did not land him in much trouble, and if they did (when other people around him get annoyed) he seemed to be able to shrug it all off. His personality has become much more placid and relaxed about almost everything, and this is helping him cope with setbacks. The fact that he had become so placid seemed to help him cope with life's adversities.

2. Unhappiness without awareness

Patient number: 024

Age: 25 years and 4 months

Nature of Accident: Motorcycle accident

Time post-injury: 6 years and 10 months

PTA: 2.5-3 months

Cognitive Deficits: No neuropsychological report available

Work: Unemployed

Marital Status: Single; Lives at home with his mother

Subject 024 only seemed to acknowledge those changes that were clear on the outside, such as his speech impediment, and the fact that he is sitting in a wheelchair. He said: "*the only changes are physical, not mental*". His memory was "no worse" and his ability to concentrate was "marvellous". His mother, however, described his slurred speech, memory and concentration problems, his inability to do two things at once, his impulsive and inappropriate behaviour, his irritability, and inability to think of the consequences of his actions. She said that he tends to blame other people rather than himself for what is going wrong in his life: "It's not me, it's them". He scored in the upper third of the client sample in terms of unawareness, i.e. his mother thought he was markedly more impaired than he did. All in all, he seems to be aware of changes that are clearly visible, but not of the more subtle, mental changes.

Patient 024 stated that he is very unhappy with his life, that he is very lonely, would like to have the freedom "*to go anywhere I want*" and would love to have a partner, but cannot find one. He complained of "*loneliness*", that he "*cannot get on with people*" and in particular "*cannot get on with women*". He was confused about "*the way people think of me...I'm feeling just like everybody else...the only difference is what they think, not what I think*". He has developed a particular fondness for women's feet ("*many men like women's feet*"), and he has been involved in several incidents in which he asked women if he could touch their feet, and the women have said to him things like: "you should be locked up" and "I'll have to tell the police, because people like

you might rape somebody...". He was very upset over incidents like these, and did not really understand why the women behaved the way they do.
His mother said he was not a happy person at all "*because of what has happened to him...he feels sorry for himself...he hasn't got a girlfriend*"

To summarise, 024 was not aware of the more subtle, mental changes, and was very unhappy because people treated him differently. He blamed his situation on his physical changes, and could not see his own contribution to the fact that other people behaved differently towards him.

3. Happiness with awareness

Patient number:	010
Age:	34 years and 6 months
Nature of Accident:	Driver in car accident
Time post-injury:	6.5 Years
PTA:	"At least a month" (report from neuropsychologist)
Cognitive Deficits:	"The major cognitive sequelae are an impairment of verbal memory, such that his ability to retain and retrieve information is impaired"; "There has been a noticeable change in temperament. Formerly a placid and easy-going person, he now tends to be impatient and irritable"; "Functional loss of the preferred left arm (From the neuropsychological Report)
Work:	Full-time work
Marital Status:	Married

010 said he has "*memory problems, I tend to forget all sorts of things*", "*I blow my top more often*" and "*I think I am more impulsive than I used to be*". He also "can't use my left arm as a result of the injury". His wife confirmed these disabilities and a comparison of patient- and carer-perceived neurobehavioral problems shows almost no difference between the two.

010 said he was "*happy with my life*" and "*extremely happy with the way things are going*", mainly because "*I am very lucky that I am married to a wonderful person*". The problems in his life are work-related, and not related to his traumatic brain injury. His wife confirmed there is "*not much*" he does not like about his life at the moment, because "*he tries to live every day as if it is his last*". The clinical neuropsychologist commented in her report that 010's "*remarkable adjustment to a very severe traumatic brain injury...must be due to a combination of factors, including his stable and highly-motivated character prior to the accident, the unflagging support of his wife, and the understanding of his employers…*"

4. Unhappiness with awareness

Patient number:	021
Age:	37
Nature of accident:	Driver in car accident
Time post-injury:	4 years 11 months
PTA:	4 months
Cognitive Deficits:	"Very slow rate of information processing and reduced span of attention"; "Significant impairment of long-term memory…both verbal and non-verbal material"; (From the neuropsychological report)
Work:	Working part-time in business he set up himself before his accident
Marital Status:	Married with two children

021 was clearly very aware of the changes since his car accident. He said that "*remembering is well below average*" He had difficulty with "*temper control, cannot make decisions, get frustrated or angry, I cannot decide for example what to eat or watch on television*". He said he makes "*inappropriate remarks when I am talking to somebody...I think: I must not say this...but you cannot help it, even though you try*" and said that "my *wife is not married to the same person*" and "*my sense of humour has gone...I cannot understand jokes, or I understand them too late when others have moved on…*". When going through a checklist of cognitive problems, he identified problems with problem solving, decision-making, organising and planning, and ability to do two

things at once. His wife said that "*in the first year he certainly did not* [understand how he has changed since the accident], *and then slowly he did become more aware of what had happened...I would say that he does have full insight now*".

When asked whether he was happy with his life, he said, "*not at all...I am a very unhappy person*". His wife confirmed that he was "*not happy with his life and with himself, he is very discontented*".

When asked to explain what it is in particular he is unhappy about, he said: "*everything, really, except my children. My marriage was extremely happy...now our marriage is in tatters...I had my own business, was very ambitious and motivated, but now I am a shadow of my former self as far as work is concerned...The business almost collapsed...It is still my business, but I need a lot of help from my father...Also, I have no interests or hobbies any more*". According to his wife, he is unhappy about "*not being as he used to be...His lack of confidence...Lack of assertiveness...He would like to do a lot of things, but cannot do them any more...he is not as fit as he used to be...His work...His relationship with me*". Both 021 and his wife said that the only thing he is happy about in his life at the moment is his two children.

Clearly, 021 was both aware of his difficulties, and very unhappy about his life.

9.2.3.3. DISCUSSION

Four case studies were described above.

The first person was largely unaware of the mental changes, and even though this sometimes landed him into trouble (with his family and ex-wife), he did not seem to care much, and was able to shrug it all off.

The second individual was also largely unaware of the more subtle changes of his traumatic brain injury, and got into difficulty because he did not realise how he comes across to other people, and as a result, thought that the world is against him and was very unhappy and.

The third individual was fully aware of the physical and cognitive changes after his severe traumatic brain injury, but was helped largely by his very determined and dedicated wife, his own character, and the fact that his employers have let him keep his job.

The fourth participant was very aware of all the changes he has gone through since the accident, and they have clearly overwhelmed him, he is unable to cope with them, despite the fact that he still works and has a wife and two children.

It is clear then that awareness and lack of awareness do not necessarily need to be related to a particular outcome.

Lack of awareness may shield the person from his perception of a gap between the new and the old self, but may in itself create other difficulties –particularly in their contact with other people. For example, they may not understand why people react to them in a certain way, why they do not gain any promotion at work, or why they cannot find a partner. This suggests that brain injured people who are not aware of their limitations may experience problems *because* they are not aware of their problems.

Similarly, awareness of limitations is not necessarily related to a particular outcome. Brain injured people who are aware of the gap between the new and the old self, may be overwhelmed by it, may not know how to scale down expectations or may not want to. There are many possible reasons (to do with the person, the environment, or the injury) why they are unable to bridge the gap between the old and the new self.

Some people are aware of their limitations, and even though they may have gone through a period of depression (as 010 did), they may have come out at the other end, and the limitations as a result of the traumatic brain injury no longer diminish their happiness.

9.3. THE RELATIONSHIP BETWEEN ACCEPTANCE OF LIMITATIONS AND SUBJECTIVE OUTCOME

9.3.1. Introduction

The literature suggests that 'Acceptance of limitations' is positively related to subjective outcome following illness (see section 3.4.). This section investigates the relationship between 'acceptance of limitations' on the one hand, and ratings of satisfaction and adjustment on the other hand in a group of severely brain injured people. First, the strength of the relationship will be tested in a quantitative analysis, and then the nature of the relationship will be explored further in a qualitative analysis.

Only brain injured people who did actually suffer from consequences as a result of their traumatic brain injury were selected for the study. Otherwise, there would not have been any limitations to accept.

9.3.2. Procedure

'Acceptance of Limitations' was assessed using the 'Acceptance of Illness Scale'. More information on this scale can be found in section 5.4.4.3. and a copy can be found in appendix 5.4.

Qualitative analysis of the interviews with the brain injured people and their carers was used to clarify the results of the statistical analysis.

9.3.3. Results

9.3.3.1 THE RELATIONSHIP BETWEEN ACCEPTANCE OF LIMITATIONS AND RATINGS OF SATISFACTION

Table 9.3. shows the one-tailed Pearson correlations between the Acceptance of Limitations Scale and subjective quality of life and also the one-tailed Spearman correlations between the three 'acceptance judgements' by the brain injured person with subjective quality of life.

TABLE 9.3. Pearson and Spearman correlations between 'Acceptance of Limitations' as perceived by the brain injured person and ratings of satisfaction and adjustment.

	Acceptance of [1] Limitations N = 44
SWLS	.62 * * *
"How do you feel about your life?"	.65 * * *
Anxiety	-.47 * *
Depression	-.68 * * *
Self-esteem	.75 * * *

(a) * * Represents a significant correlation at $p < .01$
(b) * * * Represents a significant correlation at $p < .001$
(c) The testing of the significance of correlations was one-tailed

The results show that the Acceptance of Limitations Scale was highly significantly correlated with the Satisfaction with Life Scale ($r = .62$; $p < .001$).

The Satisfaction with Life Scale was significantly correlated with acceptance judgements by the

A partial Pearson correlation between the Acceptance of Limitations Scale and the Satisfaction with Life Scale, controlling for the effects of 'awareness of deficits' was carried out in order to determine the role of awareness the relationship between acceptance and satisfaction. This

[1] The total score of the 7-item 'Acceptance of Illness Scale', filled in by the brain injured person. These are Pearson correlations.

partial correlation had a value of .60, similar to the correlation shown in table 9.3. It would therefore seem that the correlation between acceptance of limitations and global satisfaction is the same, irrespective of the level of awareness the brain injured person has gained.

These results indicate that the more the brain injured person indicated that he had accepted his limitations, the higher the brain injured person rated himself in terms of satisfaction.

9.3.3.2. THE RELATIONSHIP BETWEEN 'ACCEPTANCE OF LIMITATIONS AND OTHER MEASURES OF ADJUSTMENT

Table 9.3. also shows the Pearson and Spearman correlations between Acceptance of limitations as perceived by the brain injured person, the carer, and the researcher on the one hand and other measures of adjustment on the other hand.

The table shows that the 'Acceptance of Limitations Scale' was significantly related to level of anxiety ($p = -.47$; $p < .01$), depression ($r = -.68$; $p < .001$), and self-esteem ($r = .75$; $p < .001$). More acceptance is therefore associated with better overall adjustment.

The table also shows that 'acceptance of limitations' was particularly highly and significantly correlated with self-esteem ($r = .75$; $p < .000$).

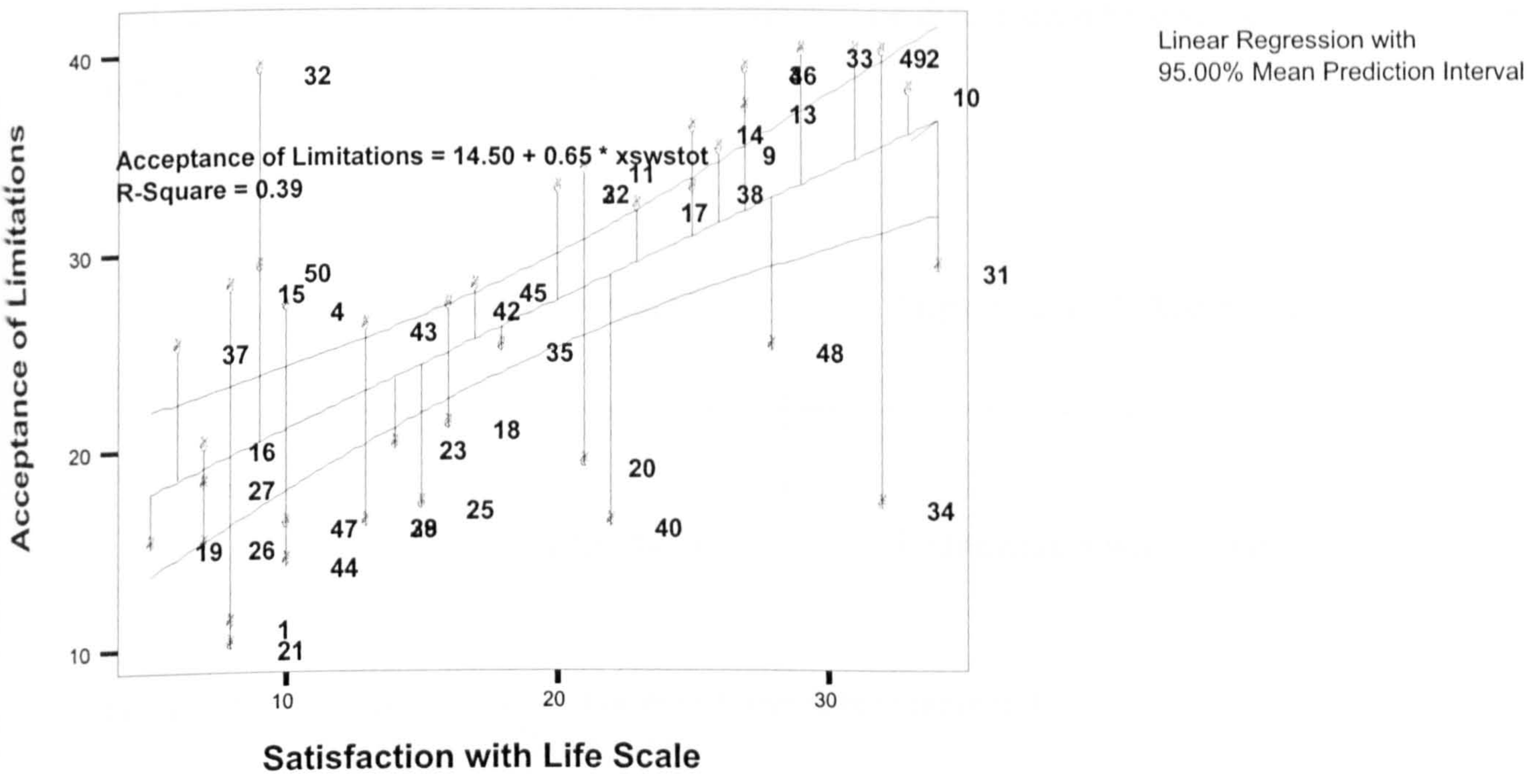
9.3.4. Qualitative analysis of 'Acceptance of Limitations' and Subjective Outcome and Adjustment

9.3.4.1. INTRODUCTION

This section will examine more closely why the relationship between acceptance of limitations and subjective quality of life is relatively high and why some people do not conform to the rule 'people with more acceptance of limitations are happier'. The first two case studies will therefore describe two brain injured people who follow this rule: one who is happy and who has

accepted his limitations (case study 4), and one who is unhappy and who has not accepted his limitations (case study 2). The first and third study will attempt to illuminate why the rule 'those who have accepted are happier than those who have not accepted' may not hold for every brain injured person (and therefore why the relationship is not 100%). The first case study describes a brain injured person who has accepted his limitations, but is still unhappy, and the third case study describes a brain injured person who has not accepted and is happy.

Figure 9.3. Regression Plot of the Relationship between 'Acceptance of Limitations' and scores on the Satisfaction with Life Scale for every brain injured person



9.3.4.2. Four possible Relationships between Acceptance of Limitations and Happiness

Figure 9.3.. shows a scatterplot of the relationship between the Acceptance of Limitations Scale on the one hand, and the main measure of global satisfaction: The Satisfaction with Life Scale. The figure suggest that overall, there is a clear linear relationship between acceptance of limitations and global satisfaction. This is also shown by the relatively high correlation

between acceptance and global satisfaction found in the previous section. However, a number of participants do not fit this linear relationship. In the appendix, this is clear because of the distance between the scores of these participants and the regression line. Some of these 'outliers' will be discussed, as will two participants who do conform.

As in the case of the relationship between awareness and happiness, four possible extreme theoretical relationships are possible between acceptance of limitations and happiness (see figure 9.4.). Four case studies will be discussed to illuminate the exact nature of the relationship between acceptance of limitations and happiness in each case.

Two people will be discussed whose scores lie close to the regression line between acceptance and subjective quality of life, and two people will be discussed whose scores do not lie close to the regression line (see figure 9.3.).

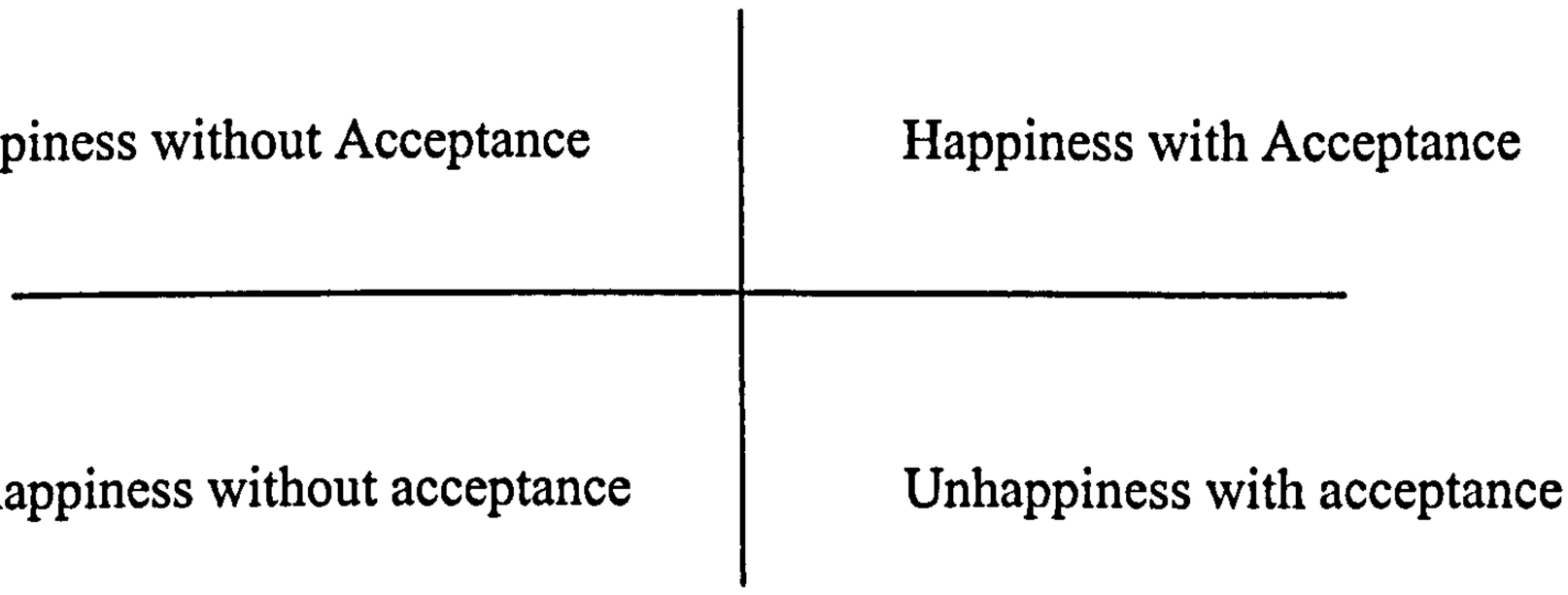


Figure 9.4. Four possible relationships between happiness and acceptance of limitations

1. Unhappiness with Acceptance of Limitations

Patient number:	032
Age:	34 years and 10 months
Nature of Accident:	Driver in car accident
Time post-injury:	11 year and 4 months
PTA:	"at least 3 weeks" (report from clinical neuropsychologist)

Cognitive Deficits: "a selective impairment of verbal memory, both short-term span and verbal working memory"; "The more significant impairment was of long-term verbal memory"; "Slowness in information-processing"; "Residual impairment of taste and smell".

Work: "Project engineer"

*Marital status:*Single

032 Acknowledged that he had lost his sense of taste and smell, that he has a slight restriction of movement in his left leg and that "*if there's a lot of new information coming at me, I find it difficult*", that he is more impulsive (*"..I say something ...I wish I hadn't*") and that he tires easily. He also said that he often knows he needs to do things at work, but then feels he lacks the confidence. He thinks a lot of information at work "*does not sink in*" and often needs to read manuals in order to know what to do.

He said he is very unhappy about his life and "*that is a definite no...*", because "*nothing has gone as I planned or wished...I would love to have a full social life, a family...children...[but] friends disappeared after I left school...[and] I wasn't in any social group...it's been like that ever since...*". He has considered suicide, and still considers it an option: "*give me a pill now and I wouldn't wake up in the morning...I'd take two to be sure...*" and "*I often think about how I'd do it...gassing myself in the car...[a car is] coming the other way and I think 'Well I ought to do it now*'".[1] His parents (who live nearby) were largely unaware of all this because he does not tell them anything about his misery. They think he is very happy with his life and that nothing is the matter.

032 Felt he has accepted his limitations as a result of his traumatic brain injury. On the Acceptance of Limitations Scale, he strongly disagrees with the statements: "I have a hard time adjusting to the limitations of my traumatic brain injury", "Because of my traumatic brain injury, I miss the things I like to do most", and "My traumatic brain injury makes me feel useless at times".

To summarise, 032 was very unhappy with his current life, but does not feel that his traumatic brain injury is to blame for it, or that it is still affecting his current life much.

2. Unhappiness without Acceptance of Limitations

Patient number:	039
Age:	26 years and 9 months
Nature of accident:	He was on a bicycle, which collided with a car
Time post-injury:	6 years and 10 months
PTA:	3-4 days (in report by clinical neuropsychologist)
Cognitive Deficits:	"a minor impairment in cognition"; "minor difficulties in visual memory and visual concentration/attention" "tiredness"(from report by clinical neuropsychologist)
Work:	Unemployed
Marital Status:	Engaged

The neuropsychologist suggested in his report that "*there are discrepancies between the apparent severity of the brain injury, the severity of the complaints as reported by 039 and his mother, and the picture on clinical examination*". He exaggerated the effects of his traumatic brain injury, although not much more than his mother (this is apparent from a comparison between carer- and subject-perceived neurobehavioral problems). He himself –and his parents- particularly complain of the fact that he "*can't really plan ahead*", one of the more subtle –and often unnoticed- effects of traumatic brain injury.

He was very unhappy with his life, particularly with the fact that he was still living at home with his parents while his friends have moved on, have good jobs and have started families. He has tried to commit suicide twice, and occasionally alludes to the fact that he will probably try again: "*Would I try it again? Probably, almost certainly…*". His parents also think he is not happy about his life, particularly his "*loss of independence*" and the "*lack of having a job and the status that goes with being employed plus the money that goes with it…*".

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[1] His GP was aware of his suicidal ideation

039 Did not feel he has accepted his limitations: "*...I am having to face up to the fact that I am not top dog, that I am nowhere near it and it's not a matter of, I'll heal, three years time you'd better watch it because I am going to be coming back, I'm not going to be coming back....*". As was clear from his scores on the Acceptance of Limitations Scale, he still very much blamed his traumatic brain injury for his current unhappiness. He agreed with statements such as "because of my traumatic brain injury, I miss the things I like to do most", "I have a hard time adjusting to the limitations of my traumatic brain injury", and strongly agreeing with "my traumatic brain injury makes me feel useless at times".

To summarise, 039 seemed to be very much aware of his limitations as a result of his traumatic brain injury, and did not seem to have accepted them yet as part of his 'new self'. He clearly blamed his traumatic brain injury for his current predicament. He is a very unhappy person to the extent that he is contemplating suicide and cannot see any positive prospects.

3. Happiness without Acceptance of Limitations

Patient number:	034
Age:	33 years and 8 months
Nature of Accident:	Passenger in work van
Time post-injury:	8 years and 3 months
PTA:	"4-5 weeks" (report from clinical neuropsychologist)
Cognitive Deficits:	"A marked loss of intellectual competence"; "some difficulty in word-finding"; Clear indications of verbal memory impairment" (short-term and long-term); "On problem-solving tasks, his performance was strongly suggestive of frontal lobe dysfunction"; "personality change" (report from clinical neuropsychologist)
Work:	Full-time, unskilled employment
Marital Status:	Lives with his girlfriend

034 Appeared to be fully aware of the consequences of his traumatic brain injury, citing the same problems as his long-standing girlfriend. He claims he is very happy with his current life.

When asked to rate himself on a scale from 1 to 10, he said: "I'd say 10, I'm extremely happy, I've got [my girlfriend]...what more could you want?".

On the Acceptance of Limitations Scale, he particularly agreed with statements such as "I object to the dependence upon others my traumatic brain injury has forced upon me", "my traumatic brain injury makes me a burden on family and friends", "Because of my traumatic brain injury, I miss the things I like to do most", and "I have a hard time adjusting to the limitations of my traumatic brain injury". However, during the interview, he seemed to suggest that he had actually accepted his limitations. His girlfriend said, when asked if he had come to terms with his limitations: "More so than he was, yes, but he has not really accepted them now".

It would appear that whether 034 has accepted his limitations or not was not terribly relevant in his life, because the overriding factor in his life is his girlfriend. He heavily relies on her and she organises his life for him.

4. Happiness with Acceptance of Limitations

Patient 010, described under 'Happiness with awareness' is a good example and could have been described here as well.

Patient number:	038
Age:	28 years and 9 months
Nature of accident:	fall off ladder
Time post-injury:	7 years and 3 months
PTA:	"7 days" (report from clinical neuropsychologist)
Cognitive Deficits:	"Short-term verbal working memory appeared to be slightly impaired"; "A moderate impairment of non-verbal visuo-constructive memory"; "an increase in irritability" (report from clinical neuropsychologist)
Work:	Computer trainer/tutor

Marital Status: Married with three children

038 thought he was slightly impaired: "My memory is definitely not what it used to be". He could not do two things at once, and was more irritable than he used to be. His wife confirmed these same disabilities, and it would therefore appear that he was aware of the way he has changed.

He said he is generally a happy person*: "I am about 8* [on a scale from 1 to 10]*...I never like to fall out or try to worry about things you shouldn't do, so yes, generally happy...*". His wife confirmed these sentiments, and his scores on the satisfaction with Life Scale and his domain-specific satisfaction ratings also backed it up.

In terms of acceptance, he strongly disagreed with the statement "I have a hard time adjusting to the limitations of my traumatic brain injury" and "My traumatic brain injury makes me feel inadequate". He also disagreed with the statements "Because of my traumatic brain injury, I miss the things I like to do most", and "My traumatic brain injury makes me feel useless at times". 038 said that adjusting "*was hard to start with...[but] you get used to it...I was young and I knew I could get over it. I wouldn't let anybody stop me, so I just got on with it...I don't struggle* [with the consequences]". His wife thought that he had a hard time adjusting to the fact that he had certain limitations, but responded with "*yes, yes...*" when asked if he had adjusted now.

Overall, it would seem that 038 had some consequences of his traumatic brain injury, but they did not seem to interfere with his life very much any more. He worked, and spent much time with his family. His memory problems and increased irritability were simply aspects of him that he and his family have learned to cope with.

9.3.4.3. DISCUSSION

Four case studies were described above.

The first individual was very unhappy with his present life, but did not feel that his traumatic brain injury was to blame for it (and said he has accepted his limitations)

The second person was also very much aware of the gap between the old and the new self, did not accept his new self, and was very unhappy.

The third person was very happy because there was another factor besides his traumatic brain injury in his life (i.e. his wife), and he would appear to be happy *despite* his traumatic brain injury.

The fourth was quite happy with his life. He had learned to live with the consequences, and they have simply become part of him, of his new self.

Overall, the relationship between acceptance of limitations is relatively high, but case studies 1 and 3 are reminders that the correlation is not 100%.

The relationship between acceptance and happiness was not necessarily 100% because people may have accepted the limitations as a result of the traumatic brain injury, but that does not mean that there cannot be other reasons to be unhappy, or to be of an unhappy disposition. As case number 3 illustrated, there may be other factors in the person's life which are more important than the consequences of the traumatic brain injury.

Cases 032 and 039 (the fist two described above) suggested that *attribution* may play a role. 032 was unhappy, but did not attribute it to his traumatic brain injury, and therefore claimed he had accepted the limitations of his traumatic brain injury. 039 was very unhappy with his life, and completely blamed his traumatic brain injury for it.

9.4. THE RELATIONSHIP BETWEEN PAST-FUTURE ORIENTATION AND SUBJECTIVE OUTCOME

9.4.1. Introduction

This section will investigate the relationship between the brain injured person's 'past-future orientation' on the one hand, and subjective outcome and adjustment on the other hand. The following three hypotheses, described in chapter five, will be tested:

Firstly, Brain injured people who look towards the past have a lower subjective quality of life than control participants who look towards the past, given the fact that they have a pre-injury past which may be perceived of as 'more glorious', whereas the controls do not necessarily have such a 'glorious past'

Secondly, brain injured people who often compare their present situation to their situation before the accident, are less well adjusted than people who do not make such comparisons.

Thirdly, brain injured people who compare their present situation to their situation directly after the accident, are better adjusted than people who do not make such comparisons.

Finally, after investigating the strength of the relationship between past-future orientation and subjective outcome quantitatively, the nature of the relationship will be explored in a qualitative analysis.

9.4.2. Procedure

'Past-future orientation' was investigated in two ways.

First, brain injured people filled in the 'Future Expectations Scale', which contains a question which requires the person to rate – on a 7 item scale- whether he looks more '*towards the past or the future'* (see Appendix 5.4.). Possible answers ranged between '*definitely the past*' and

'*definitely the future*'. The middle answer was '*neither the past nor the future*'. Forty five brain injured people answered this question.

Second, the brain injured person and his significant other were extensively questioned over his past-future orientation. These questions concerned the existence of any contrast effects: "*Do you (does he) ever think about the things you (he) could do before your (his) accident, but cannot do anymore?*", and "*Do you (does he) ever think about the things you (he) could not do after the accident, but can do now*"? These questions were coded in simple 'yes' and 'no' categories.

Both the brain injured person and his carer were given the option to classify their responses into three different categories.

The contrast effects (both 'pre-injury – present comparison', and 'post-injury – present comparison') were classified into three categories:

1. Never thinks about the things he could do before the accident
2. Sometimes thinks about the things he could do before the accident
3. Often thinks about the things he could do before the accident

The same categories (with different wording) were used for the 'post-injury – present' coding. These categories are at ordinal level, and non-parametric statistics were therefore used for the quantitative analysis. 'Pre-injury – present' comparison was classified for 27 brain injured people, and 'post-injury – present' comparison was classified for 21 brain injured people.

Non-parametric correlational data were used for the same reasons as described in section: to make comparison with the strength of the association between 'past-future orientation' and subjective quality of life possible, and because of the small number of people in each cell.

Distributions for 'preinjury-now comparison', and 'postinjury-now comparison' are printed in appendix 9.1. It clearly shows that the distribution of 'preinjury-now comparison', and 'postinjury-now comparison' were skewed. Because of the low number of people in each cell, and the fact that the distributions were skewed, power analyses were used to avoid making type II errors.

Many brain injured people did not remember exactly what they were like directly after the accident. The total number of people in the 'comparison postinjury-now' group was therefore only 21. The others were scored as missing data.

9.4.3. Results

9.4.3.1. The Relationship between past - future orientation and Ratings of Satisfaction and Level of Adjustment

Table 9.4. shows the correlations between past-future orientation, break with the past (brain injured person and the significant other) on the one hand, and ratings of satisfaction and level of adjustment on the other hand. The power of each significant correlation is shown between brackets.

TABLE 9.4. Spearman correlations between 'past-future orientation' and 'break with past' and ratings of satisfaction and measures of adjustment. The power of the Spearman test is written between brackets.

	Past - future orientation N = 45
SWLS	.59 * * * (>.99)
"How do you feel about your life?"	.67 * * * (>.99)
Anxiety	-.48 * * * (>.97)
Depression	-.62 * * * (>.99)
Self-esteem	.41 * * (>.86)
Acceptance	.44 * * (>.93)

(a) * * Represents a significant correlation at $p < .01$ (one-tailed)
(b) * * * Represents a significant correlation at $p < .001$ (one-tailed)

A clear, significant relationship was found between past-future ratings by the brain injured person (on the 7-point scale), and all ratings of satisfaction and measures of adjustment. The power of these correlations was satisfactory. This indicates that the more brain injured people said they look towards the past (as opposed to the future), the less satisfied they were with their life, and the less well adjusted they were.

Overall, it can be concluded that 'past-future orientation' was significantly correlated with ratings of satisfaction and measures of adjustment

9.4.3.2. COMPARISON WITH THE NON-CLINICAL SAMPLE

It is clear now that brain injured people who looked towards the past were less satisfied with their life than brain injured people who looked more towards the future. The next question is whether the same is true for the control sample (described in detail in section 5.5.2.).

Appendix 9.2. shows the distribution of 'past-future orientation' of both the brain injured and the control sample. It shows that the distribution of answers given to this question was similar.

Table 9.5. Comparison between the brain injured sample and the non-clinical sample in terms of answers given to the question "Do you look more towards the past or

the future?" and their Pearson correlations with the Satisfaction with Life Scale.

	Brain injured Mean N = 48	**Controls Mean N = 49**
Satisfaction with Life Scale	18.33 (s.d.8.82)	19.33 (s.d. 7.53)
	Not significant	
"Do you look more towards the past or the future?"	3.93 (s.d. 1.62)	4.25 (s.d. 1.19)
	Not significant	

	Past – future orientation r	**r**
Satisfaction with Life Scale	.61 * * *	.12
"How do you feel about your life?"	.67 * * *	.04

(a) * * * Represents a significant correlation at $p < .001$

Table 9.5. shows a comparison between the brain injured sample and the non-clinical sample in terms of their past - future orientation.

An independent samples t-test suggested that there was no difference between the two groups on the Satisfaction with Life Scale. A Mann-Whitney independent samples test[1] was used to compare the two groups in terms of their answers given to the question "*how do you feel about your life*?" No significant difference was found between the two groups. See section 7.3.1. for the test statistics.

However, when correlated with global ratings of satisfaction, an interesting picture arose. Past - future ratings by the brain injured group were highly significantly, and positively related to the Satisfaction with Life Scale ($r = .61$; $p < .001$) and the question "*How do you feel about your life?*" ($r = .67$; $p < .001$). This means that brain injured people who looked more towards the

[1] Non-parametric statistics were used for this comparison because the scoring of this question (from 'very dissatisfied' to 'very satisfied') was judged to be at ordinal level.

past rated themselves as significantly less happy than those who rated themselves as looking more towards the future.

The same effect was not observed, however, in the control group. Past - future ratings were not related to the Satisfaction with Life Scale (r = .12), nor the question "*How do you feel about your life?*" (r = .04). People who have not had a traumatic brain injury who looked more towards the past than the future, were therefore not any less happy than those who look more towards the future than the past.

These results imply a clear difference between the brain injured group and the control sample. Brain injured people who claim they look much towards the past are unhappier than brain injured people who look more towards the future. The same results were not found in the control sample.

The first hypothesis can therefore be confirmed: brain injured people who say they look towards the past have a lower subjective quality of life than controls who say they look towards the past.

9.4.3.3. COMPARING THE PAST WITH THE PRESENT

9.4.3.3.1. Introduction

The previous sections have made it clear that 'looking more towards the past than the future' is related to a negative subjective outcome in the brain injured sample (but not in the control group). This section will look more closely at the *process* of looking towards the past: what is it exactly that makes looking towards the past less beneficial?

In section 4.6.3., it was argued that people who contrast a more 'glorious' past with the present are less happy than people who do not make such comparisons. Similarly, it was hypothesised in section 4.6.3. that people who contrast a less 'glorious' past with the present are happier than people who do not make such comparisons. This theory will be tested in this section.

Brain injured people were asked whether they "*ever think about the things they could do before the accident, but cannot do anymore*". They were also asked whether they "*ever think about the things they could **not** do directly after the accident, but can do now*" because they have recovered. The first was called the comparison 'pre-injury - present', the latter was called the comparison 'post-injury - present'. The answers of brain injured people were coded into three possible categories: never, sometimes, and often. Non-parametric Spearman correlations were then used were then used to investigate the effect of these comparisons on ratings of global satisfaction and adjustment and domain-specific satisfaction (table 9.6.).

Table 9.6. *Spearman Correlations between brain injured people's comparisons 'pre-injury - now' and 'post-injury - now' and global ratings of satisfaction and adjustment. The power of the significant correlations is shown between brackets.*

	pre-injury -present N = 27	**post-injury –present N = 21**
SWLS	-.25	.34
"How do you feel about your life?"	-.49 * * (>.80)	.33
Anxiety	.09	-.12
Depression	.41 * (>.54)	-.44 * (>.53)
Self-esteem	-.43 * (>.60)	.40 * (>.42)
Acceptance	-.44 * (>.60)	.54 * * (>.77)

(a) * Represents a significant correlation at $p < .05$
(b) * * Represents a significant correlation at $p < .01$

Given the number of correlations, the significance level of a meaningful statistical correlation will have to be adjusted in order to reduce the chance of making a type I error. However, it was argued earlier that the results in this section are speculative because of the low number of people in each cell and because the distribution of the data is skewed. The results in this section may therefore be treated as 'trends that deserve further investigation'. As such, p values over .01 and below .05 are also shown.

9.4.3.3.2. Relationship between Pre-injury - Present Comparison and subjective Outcome and Adjustment

Pre-injury - present comparison was significantly related to the question "*How do you feel about your life?*" ($r = -.49$; $p < .01$; power level: 80%). This shows that people who often think about the things they could do before the accident, but cannot do anymore rate themselves as unhappier than people who do not do so. The relationship between the Satisfaction with Life Scale and pre-injury - present comparison was not significant ($r = -.25$; $p = .149$).

All other significant correlations did not reach sufficient power levels (i.e. above 80%).

Those brain injured people who never think about the way they were before the accident therefore rated themselves higher in terms of their satisfaction with life in general and in terms of their satisfaction with themselves.

9.4.3.3.3. The relationship between 'Post-injury – Present Comparison and subjective Outcome and Adjustment

Post-injury - present correlations were *not* significantly related to ratings of satisfaction.

'Post-injury - present comparison' was significantly related to Acceptance of limitations ($r = -.54$; $p < .01$). However, the power of this correlation is under the critical level of 80%.

9.4.3.3.4. Conclusions

It was found that brain injured people who often think about their life before their injury and compare it to their present situation rate themselves lower in terms of their global subjective quality of life than brain injured people who do not compare their pre-injury situation with the present. This result seems to partly confirm the second hypothesis in this section.

However, brain injured people who often think about the way they were directly after the injury and compare it to their present situation do not appear to have a higher subjective quality of life than people who do not do so. These results therefore do not confirm the third hypothesis. One confounding factor in this analysis was, however, the low number of people in each cell, and the results presented were interesting enough to warrant future investigation.

9.4.4. Qualitative Analysis: Four possible relationships between 'past-future orientation' and happiness

9.4.4.1. INTRODUCTION

The pattern is familiar now: as in the case of the relationship between happiness on the one hand and awareness and acceptance of limitations on the other hand, four theoretical relationships are possible between 'break with the past' and happiness. Four case studies will be discussed to attempt to illuminate the nature of the relationship between acceptance of limitations and happiness in each case. As with the case studies following the section on 'acceptance', the following case studies attempt to illuminate the relationship between past-future orientation and happiness. The first two cases are 'typical' cases which conform to the rule: those who look towards the past are unhappier than those who look towards the future. The first case study is happy and looks towards the future and the second one is unhappy and looks towards the past. The third case study will illuminate why the rule 'those who look towards the past are unhappier than those who look towards the future' may not hold for every brain injured person (and therefore why the relationship is not 100%).

Figure 9.5. Regression Plot of the Relationship between 'Past – Future Orientation' and scores on the Satisfaction with Life Scale for every brain injured person

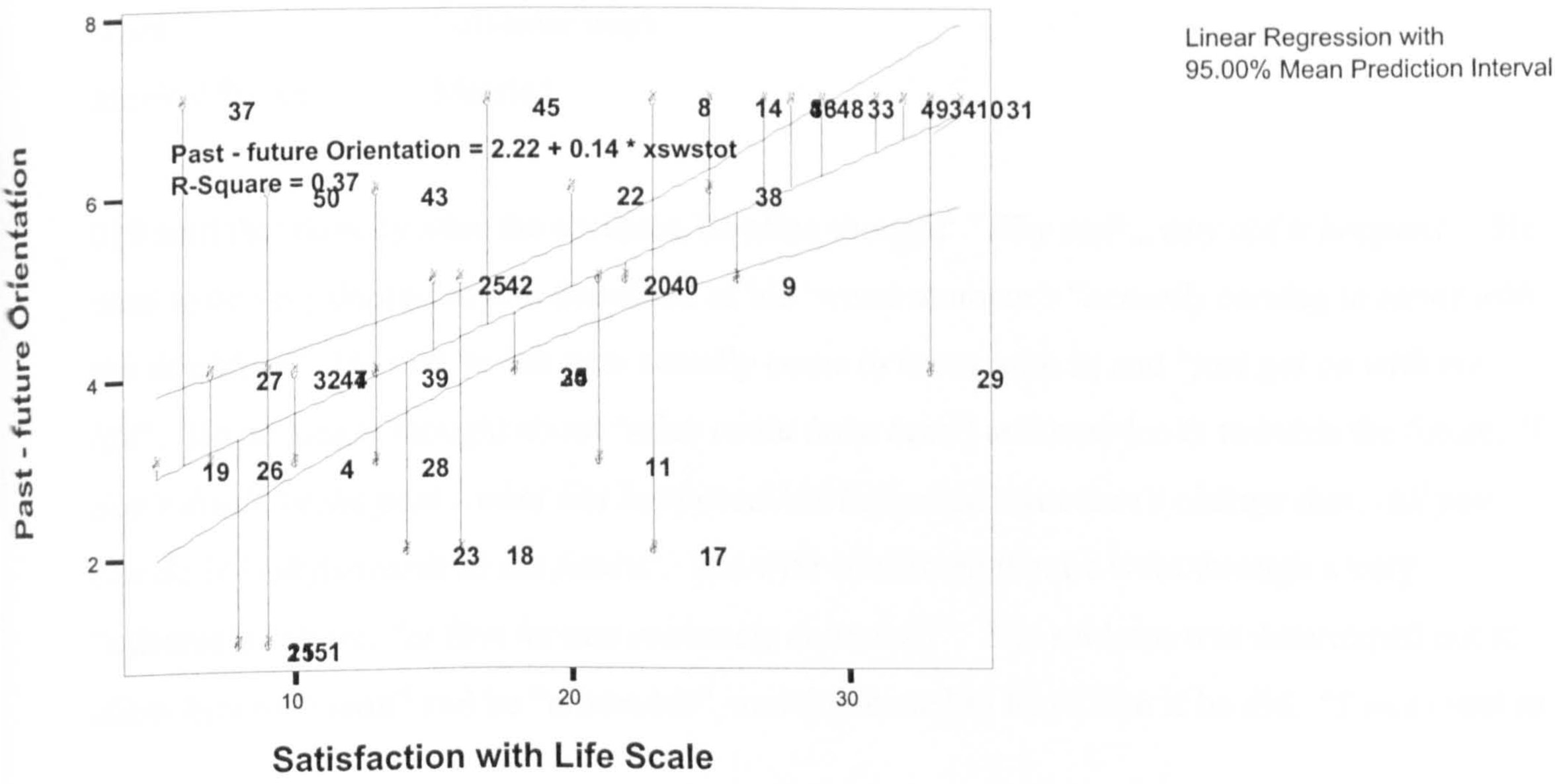

Figure 9.5. shows a scatterplot of the relationship between 'past-future orientation' and the Satisfaction with Life Scale. Overall, the relationship is relatively high, as has been shown in the above sections. There were, however a number of outliers. These will be discussed below.

1) Happiness and looking towards the future

An excellent example of a person who is satisfied with his life, and who looks towards the future is participant 010, who was also discussed under 'happiness and awareness'.

Patient number:	010
Age:	34 years and 6 months
Nature of Accident:	Driver in car accident
Time post-injury:	6.5 Years
PTA:	"At least a month" (report from neuropsychologist)
Cognitive Deficits:	"The major cognitive sequelae is an impairment of verbal memory, such that his ability to retain and retrieve information is impaired"; "There has been a noticeable change in temperament. Formerly a placid and easy-going person, he now tends to be impatient and irritable"; "Functional loss of the preferred left arm (Report by neuropsychologist)
Work:	Full-time work
Marital Status:	Married

010 said that directly after the accident, he often thought: "*Why me?...why did it happen?*". He used to be very depressed and described as his 'worst moment': "*actually coming to terms with the disability*". He said he has now actually come to terms with it, and "*just got on with my life*". He no longer thought about "*what could have been*" and now looks towards the future: "*I don't dwell on the past...what has happened has happened...you can't change that...all you can do is look forwards to the future*". His wife confirmed that he went through a very "miserable" phase: "*at first he was extremely depressed*". She said she was determined not to allow him to "*moan*" and be "*miserable*", and threatened to leave him if he did. "*I was cruel to*

be kind, I think...but it worked...". She said he had "*definitely*" accepted the limitations as a result of his accident; he looked "*towards the future*", and there had been a clear break with the past.

2) Happiness and looking towards the past

As can be seen in figure 9.5., it was not possible to find a person who looked towards the past and was satisfied with his life at the same time. There were also no participants who said they had 'broken with the past' (nor carers who say the participant has broken with the past) who, at the same time claimed they were happy with their life. 017 came closest, but he was unfortunately not interviewed.

3) Unhappiness and looking towards the past

A very good example of 'unhappiness without a break with the past' is participant 021, who was also discussed under 'unhappiness with awareness'. (039, who was discussed under 'unhappiness and no acceptance' also would have been a good illustration of this category).

Patient number:	021
Age:	37
Nature of accident:	Driver in car accident
Time post-injury:	4 years 11 months
PTA:	4 months
Cognitive Deficits:	"Very slow rate of information processing and reduced span of attention"; "Significant impairment of long-term memory...both verbal and non-verbal material"; (Assessment at Rivermead rehabilitation Centre in Oxford)
Work:	Working part-time in business he set up himself

Marital Status: Married with two children

021 was very much aware of his disabilities, and scored very low on acceptance ("*I do not accept my injuries...I have not learnt to live with them or cope with them at all...*"). He also stated that he still very much lives in the past: *"I very often think about it..."*, particularly about the way he was before the accident: "*I do think about the way I used to be a lot...*", and not so much about the way he was directly after the accident. His wife confirmed all this.

Overall, 021 was a very bitter, disappointed person. He could see clearly how he had changed, often thought about his old self, had not accepted his new self, and spent much time thinking about what he had lost.

4) Unhappiness and looking towards the future

Patient number: 037

Age: 24 years and 11 months

Nature of Accident: Motorcycle accident

Time post-injury: 8 years and 1 month

PTA: More than a month

Cognitive Deficits: "The diffuse effect is slowness in information processing, in both intellectual and motor domains"; "The selective effects are still apparent on tests of word retrieval, memory, and sustained attention"; "The personality change remains one of the major sequelae...irritability and aggression".

Work: Electrical Fitter

Marital Status: Single

When asked, 037 mentioned all the cognitive and personality problems described above. His mother confirmed them, and a comparison of participant- and carer-perceived neurobehavioural problems showed that 037 may even have exaggerated his own problems. It would therefore seem that he was very much aware of how he had changed from before the motorcycle accident.

His Satisfaction with Life Scale score was the lowest of all brain injured participants. He said he was unhappy because of concerns over money (bills), his current job, his house, and the lack of friends (he has lost quite a few friends since the accident). He said the last 10 years have been "*an uphill battle*" but that things were "*getting slightly better now*". His mother thought he was depressed, but he refused to go and see GP. She thought that he had changed slightly over the last year and she "*can begin to see 037 back*". She was not sure if he had accepted his limitations, but didn't think so.

Regarding his 'past-future orientation', he said: "*I don't think about the past at all, I concentrate on the future. I very, very rarely think about the accident or the past. Well, obviously I can't because of my memory...I am conscious of the disabilities because they are still there, but the accident and all that, I don't think about it at all*". When asked if he ever compared himself to the way he was before the accident, he replied "*Yes, but then again I have to make myself happy in the future and not worry about how happy I was in the past*".

Overall, it would seem that 037 was very unhappy with his current life. Yet where most brain injured people in his position often think about the past, he didn't seem to for two reasons: Firstly, he could not remember the accident and everything that happened afterwards. Secondly, he did not think it was helpful to think about the past and made a conscious effort not to, because he wanted to focus on the future.

9.4.4.2. DISCUSSION

Three case studies were described above.

For the first individual, the past did not seem to be relevant any longer. The traumatic brain injury and its consequences had become part of his and his wife's life. He was happy about his current life, and seemed to experience all the normal hopes and worries of non-brain injured people.

The second participant was fully aware of the consequences (the gap between the old and the new self), had not accepted his new self, and was also trapped in the past, constantly comparing himself the way he used to be with the way he is at the moment.

The third participant was –again- fully aware and very unhappy. He did not look towards the past for two reasons: he could not remember the accident and most of what had happened to him over the last 10 years. Secondly, he did not think it was helpful to compare himself the way he was to his present self.

Overall, it would appear that there was quite a strong relationship between looking towards the past, comparing the old self to the present self, and unhappiness. Case studies 1 and 3 were good illustrations of this fact. The first person had been able to deal with the issues, to bridge the gap between the old and the new self, and was relatively happy with his life. The second participant was at the other end of the spectrum: trapped in comparisons between his present and the old self. He was very unhappy, and was unable at present to bridge the gap.

However, the link between past-future orientation and satisfaction was not 100%, and the third case study provided some clues why this is the case. He did not remember the accident (just like all the others), and also said he could not remember everything that had happened to him after the accident. Although this 'protected' him from thinking too much about all the negative experiences, it obviously did not protect him from thinking about the way he was *before* the accident. However, he said he consciously made an effort not to think about the past, because he needed to focus on the future. Unfortunately for him, there was enough in the present to make him unhappy. Not thinking about the past may in this case actually have protected him from more worries. This was nicely formulated by another participant (025): "*I just decided not to think about the past, because it hurts me when I look at the past, and when I look at it now, to see what I could have been*". Not thinking about the past was therefore in this case a coping method, as opposed to being a sign of good adjustment.

9.5 SOCIAL COMPARISON AS A MEDIATOR BETWEEN NEUROBEHAVIOURAL PROBLEMS AND SUBJECTIVE OUTCOME

Social comparison theory, as applied to the field of outcome following head-injuries, predicts that those brain injured people who compare themselves to people who have not had a head injury are worse off in terms of subjective outcome than those brain injured people who do not do so. Conversely, brain injured people who compare themselves to other brain injured people who are worse off than they are, will be better off in terms of subjective outcome than those who do not do so.

Both brain injured patients and their close relatives were asked during the qualitative interview whether they ever compare themselves to either brain injured people who are better/worse off, or to non-brain injured people.

Brain injured people and their close relatives were therefore asked during the semi-structured interview whether they engage in social comparison processes. Rather surprisingly, during the first 15 interviews, only two brain injured people said they engage in such a comparison process, and only one parent. This line of investigation was therefore not deemed to be relevant and was no longer pursued.

9.6. CONCLUSIONS

The following conclusions can be drawn from the results presented in this chapter:

- Awareness of limitations was not related to subjective outcome and adjustment; Qualitative analysis showed that there is not necessarily a relationship between awareness and subjective quality of life

- 'Acceptance of limitations' was relatively highly correlated with ratings of satisfaction, self esteem, depression, and anxiety

- 'Past-future orientation' and whether the patient had 'broken with the past' (as perceived by the participant or the carer) were relatively highly correlated with ratings of satisfaction and other measures of adjustment. This means that brain injured people who looked towards the past had a lower subjective quality of life than brain injured people who looked towards the future. The same result was not found in the control sample: the controls who looked towards the past did not have a lower subjective quality of life than the controls who looked towards the future.

- Brain injured people who often thought about their life before the accident were less satisfied with their life and less satisfied with themselves than brain injured people who did not do so;

- Brain injured people who often think about their life just after the accident did not have a higher subjective quality of life than brain injured people who do not do so .

CHAPTER TEN Subjective Aspects of the Recovery

10.1. INTRODUCTION

Chapters 7, 8, and 9 form the main course of this thesis. By the same analogy, this chapter can be perceived of as the dessert.

Firstly, it will look at another possible mediator of subjective quality of life: time post-injury.

Secondly, it will investigate one particular sign of bad adjustment: suicidal ideation and suicide attempts after severe traumatic brain injury.

Thirdly, it will look at subjective perceptions of positive experiences as a result of having suffered a traumatic brain injury.

10.2. THE RELATIONSHIP BETWEEN TIME POST-INJURY AND SUBJECTIVE QUALITY OF LIFE

10.2.1. Introduction

In section 3.5., the relationship between time post-injury and measures of adjustment was discussed for illnesses other than traumatic brain injury. The overall conclusion was that time post-injury has not been found to be related to measures of adjustment. This section will investigate whether the same is true for the brain injured sample in this study.

10.2.2. The Relationship between Time post-injury and ratings of Satisfaction and Measures of Adjustment

Figure 10.1. shows the relationship between time post-injury and the Satisfaction with Life Scale. They show that there was no relationship between the two. This is confirmed by the weakness of the Pearson correlation between time post-injury and the Satisfaction with Life Scale (r = .09, not significant) and between time post-injury and the answer to the question "How do you feel about your life?" (r = -.07; not significant).

Dividing time post-injury up into two groups (1-7 years and 7-17 years) or three groups (1-5 years; 5-10 years; 10 to 17 years) and testing for any differences between the groups did not yield any significant differences between the groups.

Overall, it can be concluded that there did not appear to be a relationship between time post-injury and ratings of satisfaction.

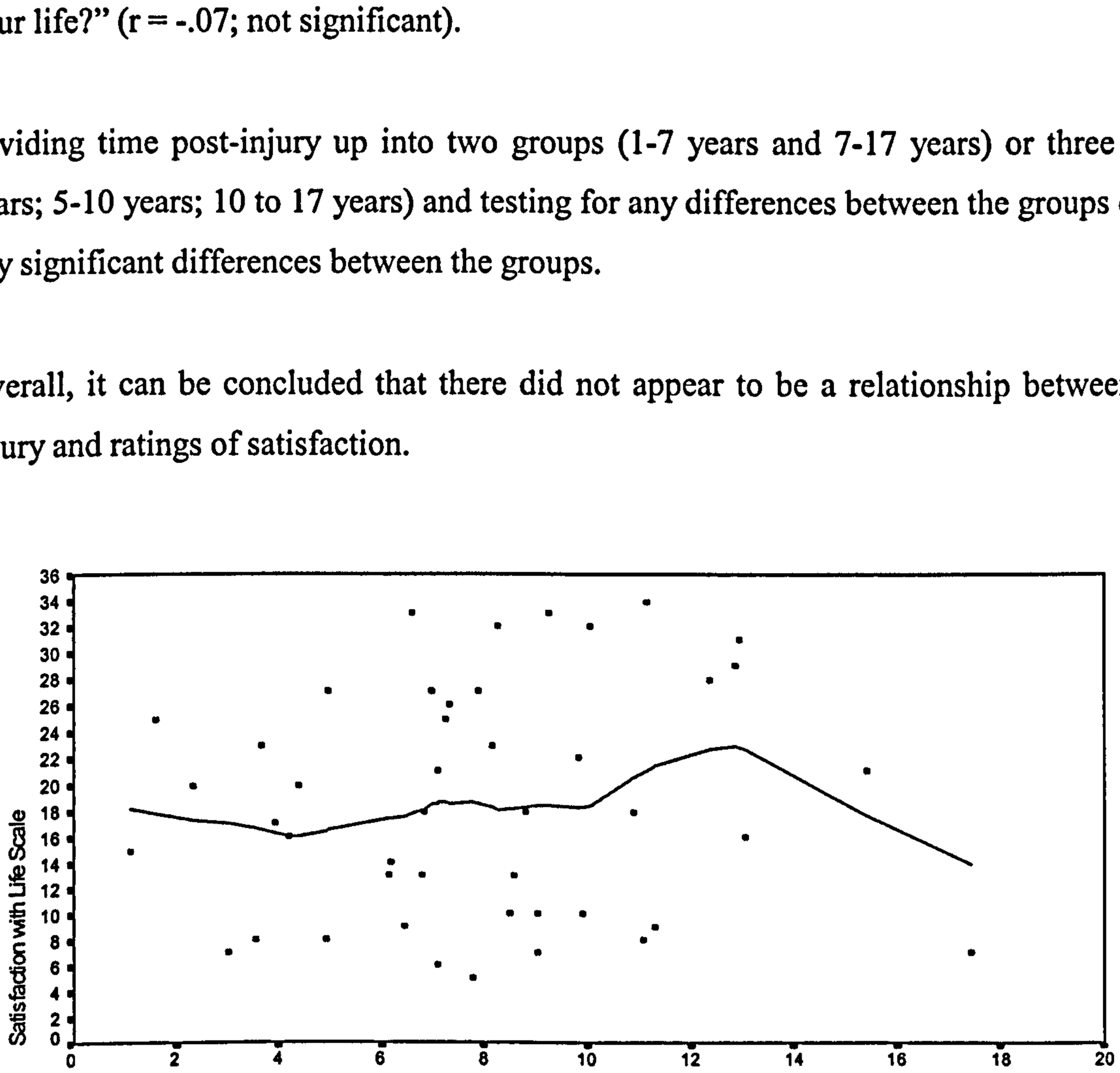

FIGURE 10.1. A scatterplot of the relationship between time post-injury and The Satisfaction With Life Scale total score. The Lowess plot fits 50% of the points.

Pearson correlations showed that there was no linear relationship between time post-injury and self-esteem (r = -.01), acceptance of limitations (r = -.05), anxiety (r = .01) or depression (r = -.09).

Dividing time post-injury up into two groups (1-7 years and 7-17 years) or three groups (1-5 years; 5-10 years; 10 to 17 years) and testing for any differences between the groups did not yield any significant differences between the groups.

Table 10.1. Pearson Correlations between Time post-injury and ratings of satisfaction and measures of adjustment (N = 49)

	Time post-injury	
	r	**p**
SWLS	.13	ns
"How do you feel about your life?"	-.06	ns
Anxiety	.10	ns
Depression	-.09	ns
Self-esteem	-.01	ns
Acceptance	-.05	ns

The results suggest that there is no significant relationship between time post-injury on the one hand and depression, anxiety, self-esteem and acceptance on the other hand.

10.3. SUICIDAL IDEATION AND SUICIDE ATTEMPTS

10.3.1. Introduction

'Suicidal ideation and suicide attempts' was looked at in the current study because it can be perceived to be a measure of the brain injured person's level of adjustment.

Brain injured people and their carers were asked whether he had '*ever thought about ending it all*'. They were then given the choice between the following four categories:

1. 'not thought about it at all';
2. 'thought about it, but never seriously';
3. 'thought about it, seriously';
4. 'has attempted suicide on one or more occasions'.

Table 10.2. shows the answers given by both the brain injured person and his significant other. It documents the brain injured person's answers, the significant other's answers, and a cumulative answer, which is the 'highest' answer of either the brain injured person or the significant other. This was done because in some cases, the brain injured person could not remember whether he had attempted to commit suicide, and in other cases he had not told the significant other about his suicide attempts.

10.3.2. Reports of Suicidal Ideation and Attempts by the brain injured sample and the significant others

Three brain injured people reported a suicide attempt when the carer did not report it. In one case (patient no. 023), the carer (father) had been interviewed, but the tape was not transcribed because he made less sense than the brain injured person.

In the second case (patient no 021), the brain injured person did not tell his wife about an attempt in which he had tried to connect the exhaust to the inside of his car.

In the third case (patient no 029) the brain injured person did not tell his parents about an overdose of pills.

Table 10.2. Reports of suicidal ideation and suicide attempts during the recovery by the brain injured person, the carer, and the cumulative answer of both (in percentages).N is between brackets..

	HI person %	**Carer %**	**Both %**
Has never considered it	26 (7)	50 (13)	29.0 (9)
Has thought about it, but not seriously	26 (7)	8 (2)	16.1 (5)
Has seriously considered it	26 (7)	11 (3)	19.4 (6)
Has attempted to commit suicide	22 (6)	31 (8)	35.5 (11)

Four carers reported suicide attempts when the brain injured person did not report it.

In the first case (patient 011), the brain injured person did not remember much about his recovery.

In the second case (patient 020), the brain injured person acknowledged that he may have done things "*because you would not care if you died or not*" but denied any suicide attempts.

In the third case (patient 024), the brain injured person himself said that he might have "*thought of it, but nothing's happened*".

The fourth brain injured person (patient 042) said, when asked if he ever thought of ending it all: "*Well, not really. I thought of it at times, but then I think it is the coward's way out*".

10.3.3. Subjective Quality of Life and Adjustment following a Suicide Attempt

Table 10.3. shows the mean ratings of brain injured people in terms of their level of satisfaction and level of adjustment for a sub group who have attempted to commit suicide (N = 11) and a sub group who have not attempted to commit suicide (N = 19).

The group of brain injured people who had attempted to commit suicide consisted of those cases in which either the brain injured person himself or his significant other indicated that a suicide attempt had occurred.

The two groups did not differ significantly in terms of post traumatic amnesia, cognitive deficits, or time post-injury. They did differ significantly in terms of carer-perceived neurobehavioural problems [$t = 2.69$; $df = 27$; $p < .01$], indicating that the carers of those brain injured people who had attempted to commit suicide rated them significantly higher in terms of neurobehavioural problems than the carers of those who had not attempted to commit suicide[1].

In order to investigate any differences between the two groups, t-tests were used. However, no differences were found. This suggests that brain injured people who had attempted to commit suicide during their recovery did not rate themselves lower in terms of their level of satisfaction, and were not less well-adjusted than brain injured people who had not attempted to commit suicide.

Table 10.3. Mean ratings of satisfaction and adjustment of those brain injured people who had not and those who had attempted to commit suicide

	Suicide attempt		**No suicide attempt**		
	M	**s.d.**	**M**	**s.d.**	
	N = 11		**N = 19**		
SWLS	20.55	8.0	19.84	8.9	ns
"How do you feel about your life?"	3.91	1.9	4.16	1.5	ns
Anxiety	7.09	5.6	7.32	4.0	ns
Depression	7.55	5.9	4.84	3.2	ns
Self-esteem	29.55	10.0	32.21	9.3	ns
Acceptance	23.88	9.1	30.05	8.6	ns

[1] Appendix 10.1. shows the means and standard deviations of brain injured people who had and those who had not attempted to commit suicide in terms of injury-related variables, subjective quality of life, and adjustment

Ns Not Significant

To summarise, in 35% of all cases, either the brain injured person or his carer reported that the brain injured person had attempted to commit suicide.

Whether or not somebody had attempted to commit suicide could not be predicted using injury-related variables, and those who had attempted to commit suicide were not less satisfied with their life nor were they any less well-adjusted than those who had not attempted to commit suicide. Unfortunately, no data were available about when the brain injured person had attempted to commit suicide.

10.4. POSITIVE CONSEQUENCES OF A SEVERE TRAUMATIC BRAIN INJURY

10.5.1. Introduction

In the literature review in section 4.9., it was found that many people report positive consequences following illness or disease. However, despite the fact that many people report these types of consequences, Lehman et al. (1993) found that perceiving positive effects from illness is not necessarily positively related to outcome. This section will investigate whether the same holds for a group of severely brain injured people.

10.4.2. Positive effects reported by the brain injured person and his Significant Other

Table 10.4. shows the percentage of brain injured people and their carers who responded with 'yes' or 'no' to the question: "*do you feel that anything positive has come out of the fact that you (he) had an accident (for him)?*"

80% of the brain injured group answered this question positively and only 20% answered it negatively. The carers, however, showed the opposite pattern, with more people thinking that it did not have any positive effects for the brain injured person (63.1%) than people who argued that it also had positive effects (37.9%). The non-parametric Wilcoxon matched-pairs signed-ranks test confirmed the significant difference in answers between brain injured people and their carers [$z = -3.05$; $p < .001$]. A matched pairs analysis was used so that a brain injured person was paired with his own carer.

Table 10.4. Positive effects of the traumatic brain injury according to the brain injured person and the carer

Positive effects	HI person	Carer
YES	24 (80%)	11 (37.9%)
NO	6 (20)	18 (63.1%)

Because of the small number of brain injured people who responded negatively to the question whether anything positive had come out of the fact that they had had a traumatic brain injury (N = 6), it is difficult to try to relate patient-perceived 'positive effects' to subjective outcome. T-tests were used to test whether brain injured people whose significant others thought there had been positive effects (N = 11) were more satisfied and better adjusted than those brain injured people whose significant others did not think there had been any positive effects (N = 18). This was not the case.

10.4.3. A Traumatic brain injury as a Learning Experience

Brain injured people were asked whether, as a result of the traumatic brain injury and going through the recovery, they felt they had learned anything in the following three areas (the same as Lehman et al., 1993):

1. Changes in self-perception

2. Understanding social relations
3. Life orientation

The responses of brain injured people are shown in table 10.5.. A Chi-square test did not distinguish between the domains, so that it can be said that one domain was not mentioned more by the brain injured sample than another.

Table 10.5. Percentage of brain injured people who said that self-perceptions, understanding of social relations, or life orientation had changed

Domain of reported change	YES	NO
Self-perception	48.1 (13)	51.9 (13)
Understanding other people	33.3 (8)	66.7 (18)
Life orientation	46.2 (12)	53.8 (13)

Table 10.6. shows the mean ratings of satisfaction and level of adjustment of those brain injured people who responded 'yes' or 'no' to the question whether they have learned anything as a result of their traumatic brain injury in terms of self-perception, understanding others, or life orientation.

Many brain injured people did not answer this question, and the numbers in each group were therefore relatively low. It is therefore difficult to draw firm conclusions from the results.

None of the comparisons actually reached this level of significance, and it can therefore be concluded that whether or not brain injured people perceive their traumatic brain injury as a learning experience was not related to their own ratings of their satisfaction or to any of the measures of adjustment.

Table 10.6. Average ratings of satisfaction and level of adjustment of brain injured people who answered 'yes' or 'no' to the question whether they have learned anything as a result of their traumatic brain injury in terms of self-perception, understanding others, and life orientation.

	Self-perception		**Understanding Others**		**Life orientation**	
	YES N=13 M	**NO N=13 M**	**YES N=8 M**	**NO N=18 M**	**YES N=12 M**	**NO N=13 M**
Satisfaction with Life Scale	23.69	20.15	20.75	22.44	21.17	22.31
"How do you feel about your life?"	5.00	3.69 *	4.00	4.53	4.33	4.23
Anxiety	5.62	7.38	8.25	5.72	5.67	7.31
Depression	4.08	6.31	7.88	4.00 *	4.58	6.00
Self-esteem	35.00	29.69	29.67	33.76	33.36	30.93
Acceptance	29.45	27.00	25.56	29.67	29.3	26.69

* Indicates a significant difference at $p < .05$ (2-tailed)

10.4.4. Positive Personality Change

A number of brain injured people (and their significant others) pointed out that the traumatic brain injury has been a positive experience, because it stopped them from 'going off the rails', and made them more placid, understanding, and kind.

015 was, according to his parents, "*on the road to...self-destruction*" when he had his accident. He was drinking heavily, and would get behind the steering wheel with too much alcohol. His mother reckoned that if he had not had the accident, he "*probably would not be with us ...now*". The car accident he was involved in was itself the result of excessive drinking. 015 Said "*it was going to happen sooner or later*" when he was interviewed. After the accident, he showed many of the typical characteristics after traumatic brain injury: irritability, impassivity, memory problems and reduced information processing. One of the consequences of the traumatic brain injury was that it made him more sensitive to the effects of alcohol. Because of this, he gave up drinking. The self-destructive element in his character disappeared completely. And he was now "*careful about my health*". His parents claimed that "*He doesn't abuse himself like he used to*". 015 said that before the accident, he was a very closed person, but that he is much more open now. His parents added that before, he would never spontaneously show affection

Despite the positive turn his life had taken as a result of the accident, 015 was not a happy person. He said he lacked confidence. He was dissatisfied about the fact that he worked at a lower level than prior to the accident (his mother: "*015 still perceives himself as to how he was prior to the accident as far as work is concerned*"). Furthermore, he had many difficulties maintaining relationships.

045 was involved in a car accident four years prior to the interview. When asked about the consequences of his traumatic brain injury, he immediately answered "*I would actually say that I am a much better person*". He said that "*...before I was in a lot of trouble with the police...I was very violent before, and I used to shout at mum a hell of*

a lot...now...I'm not any trouble at all...I don't drink so much...and I tend to eat healthily...". He claimed that his traumatic brain injury "*has given me a new lease of life...*".

His mother and father confirmed that "*he is not the 045 he was, he's much more mild mannered, much more gentle...he has got a better disposition...he was Jack the Lad...treating people how he wanted to treat them...*"

040 Thought his traumatic brain injury "*changed my personality a bit, because it's given me a better personality...I'm nicer to live with...I used to be with a rough crowd...*". His parents thought that before the accident, 040 "*was a real bastard, he was horrible, he was a horrible kid, so it depends on what you mean has anything good come out of it. He's much nicer now than he was then...*". And: "*The good that came out of it of course is that we know, I knew, that he was very close to finishing his life when he had this accident, and anything on top of that is a bonus of course, so it depends on what you mean*".

The literature on the behavioural effects of traumatic brain injury focuses very much on the fact that brain injured people become more irritable and aggressive. These three cases illustrate that the overall effect of a traumatic brain injury on personality is not always negative, as is always assumed. Three out of a total of 36 interviews is 8.33% of the current sample whose personality has changed for the better. It is not known how many people in the control group experienced a positive personality change in the 7 years (7 years because the brain injured sample was on average just over 7 years post-injury) before they filled in the questionnaires. However, the brain injured people who did report a positive personality change clearly linked it to their traumatic brain injury.

10.5. CONCLUSIONS

The following conclusions can be drawn from the results presented in this chapter:

- There was no relationship between time post-injury and subjective quality of life and adjustment

- In 35.5% of all interviewed cases, either the participant or the carer responded with 'yes' to questions whether the brain injured person has ever attempted to commit suicide

- The significant others of those who had attempted to commit suicide rated them higher n terms of neurobehavioural problems than the significant others of those who had not attempted to commit suicide; Those who had attempted to commit suicide in the past were not less satisfied with their life nor were they any less well-adjusted at the time of interview than those who had not attempted to commit suicide.

- Brain injured people reported significantly more positive effects from the traumatic brain injury than their carers;

- Brain injured people reported they feel they have learned from having suffered a traumatic brain injury in terms of self-perception, understanding other, and life orientation. However, those who claimed to have learnt from the experience did not rate themselves as more satisfied and were not better adjusted than those who did not report such consequences.

- In at least 8% of the present sample, both the carer and the brain injured person reported a positive change in terms of their personality

CHAPTER ELEVEN Discussion and Implications

11.1. INTRODUCTION

The aim of this chapter is to discuss the results found in the study and to identify some of the theoretical and clinical implications. This chapter will restate the main aims of the project (11.2.), outline the main findings (11.3.), discuss the results (11.4.), and consider some of the clinical implications (11.5.) and suggestions for future research (11.6.).

11.2. AIMS OF THE PROJECT

This project was initially started with two main research questions in mind:

(a) What is the long-term subjective quality of life of a sample of severely brain injured people compared to a normal sample

(b) How can subjective quality of life best be predicted? In particular, this study focused on the association between subjective quality of life on the one hand and on the other hand injury-related variables and adjustment-related variables.

11.3. MAIN CONCLUSIONS OF THE STUDY

The *main* conclusions of this study are reported below:

A. SUBJECTIVE QUALITY OF LIFE

1. What is the subjective quality of life of a sample of severely brain injured people who are more than one year post-injury?

Findings:

- ⇨ Brain injured people were particularly dissatisfied with 'not having a partner' and their sexual life. They were most satisfied with their ability to take care of themselves.

2. How do the subjective quality of life and other measures of adjustment of a sample of severely brain injured people compare with the subjective quality of life of a matched, healthy control group?

Findings:

- ⇨ Brain injured people did not rate themselves less satisfied with their life as a whole than a matched non-injured control group.
- ⇨ Brain injured people rated themselves significantly less satisfied than a matched non-injured control group with the following domains in their life:
  - ◻ Mental abilities
  - ◻ Sexual life
- ⇨ Brain injured people and the control group did not differ in terms of what they find important in life.
- ⇨ Brain injured people had significantly fewer positive expectations for the future in most domains than a matched non-brain injured control group; They were, however, equally hopeful about the future in general.

B. PREDICTING SUBJECTIVE QUALITY OF LIFE

3a. What is the relationship between the subjective quality of life of a sample of severely brain injured people and a measure of the severity of the traumatic brain injury (post traumatic amnesia)?

Findings:

- ⇨ Post-traumatic amnesia was not significantly related to subjective quality of life and other measures of adjustment (depression, anxiety, self-esteem, and acceptance of limitations) in this sample of severely brain injured people.

3b. What is the relationship between the subjective quality of life of a sample of severely brain injured people and carer-perceived neurobehavioural problems?

Findings:

- ⇨ Neurobehavioural problems, as perceived by the carers, were significantly related to subjective quality of life;
- ⇨ Neurobehavioural problems, as perceived by the carers, were significantly related to depression, acceptance of limitations, and self-esteem.

3c. What is the relationship between the subjective quality of life of a sample of severely brain injured people and patient-perceived neurobehavioural problems?

Findings:

- ⇨ Self-perceived neurobehavioural problems were highly positively correlated with ratings of satisfaction, and other measures of adjustment;

3d. Through the progression from severity of the traumatic brain injury, to carer-perceived neurobehavioural problems, to patient-perceived neurobehavioural problems, the relationship with subjective quality of life becomes stronger.

Findings:

- ⇨ Self-perceived neurobehavioural problems were significantly more highly correlated with subjective quality of life than carer-perceived neurobehavioural problems and post traumatic amnesia.
- ⇨ No injury-related variable had a significantly higher or lower correlation with subjective quality of life than any other injury-related variable

4a. What is the relationship between the subjective quality of life of a sample of severely brain injured people and their level of awareness of their limitations?

Findings:

- ⇨ Awareness of limitations was not related to subjective outcome and adjustment; Qualitative analysis illustrated that there was not necessarily a relationship between awareness and subjective quality of life

4b. What is the relationship between the subjective quality of life of a sample of severely brain injured people and their level of acceptance of limitations?

Findings:

⇨ 'Acceptance of limitations' was relatively highly positively correlated with ratings of satisfaction, self esteem, depression, and anxiety

4c. What is the relationship between the subjective quality of life of a sample of severely brain injured people and their past - present - future orientation? (i.e. whether the person is still looking towards the past or has begun to look towards the future)

Findings:

⇨ 'Past-future orientation' was relatively highly positively correlated with ratings of satisfaction and other measures of adjustment. This means that brain injured people who looked towards the past had a lower subjective quality of life than brain injured people who looked towards the future.

4c-I. Hypothesis: Brain injured people who look towards the past have a lower subjective quality of life than control participants who look towards the past, given the fact that they have a pre-injury past which may be perceived of as 'more glorious', whereas the controls do not necessarily have such a 'glorious past'.

Findings:

⇨ 4c showed that brain injured people who look towards the past have a lower subjective quality of life than brain injured people who look towards the future. The same result was not found in the control sample: the controls who looked towards the past did not have a lower subjective quality of life than the controls who looked towards the future. The conclusion was therefore that brain injured people who looked towards the past have a lower subjective quality of life than controls who look towards the past

4c-II. Hypothesis: Brain injured people who often compare their present situation to that before the accident, are less well adjusted than brain injured people who do not make such comparisons.

Findings:

⇨ Brain injured people who often thought about their life before the accident were less satisfied with their life and with themselves than brain injured people who did not do so;

4c-III. Hypothesis: Brain injured people who compare their present situation to their situation directly after the accident, are better adjusted than brain injured people who do not make such comparisons.

Findings:

⇨ Brain injured people who thought about the way they were directly after the accident did not have a higher subjective quality of life than people who did not do so.

4d- I) Hypothesis: Brain injured people who compare their own situation to that of other people who have not had a head injury are engaging in upward social comparison. Their subjective quality of life is therefore likely to be lower than that of brain injured people who do not engage in such comparison.

Findings:

⇒ Brain injured people and their close relatives did not report any explicit upward social comparison processes

4d-II) Hypothesis: Brain injured people who compare their own situation to that of other brain injured people who are worse off than they are, are engaging in downward social comparison. Their subjective quality of life is therefore likely to be higher than that of brain injured people who do not engage in such comparison.

Findings:

⇒ Brain injured people and their close relatives did not report any explicit downward social comparison processes

C. OTHER ASPECTS OF THE SUBJECTIVE RECOVERY FOLLOWING SEVERE TRAUMATIC BRAIN INJURY

5. What is the relationship between the subjective quality of life of a sample of severely brain injured people and time post-injury?

Findings:

⇨ There was no relationship between time post-injury and subjective quality of life and other measures of adjustment (depression, anxiety, self-esteem, and acceptance of limitations).

6.a. Do severely brain injured people or their carers retrospectively report suicide attempts following the injury?

Findings:

⇨ In 35.5% of all interviewed cases, either the participant or the carer responded with 'yes' to question whether the brain injured person had ever attempted to commit suicide

6b. Is it possible to predict suicide attempts from injury-related data?

Findings:

⇨ Whether somebody had (reportedly) attempted to commit suicide could not be predicted using the injury-related variables post-traumatic amnesia and patient-perceived neurobehavioural problems. However, those who had reportedly attempted to commit suicide had a significantly higher score for carer-perceived neurobehavioural problems than those who had not attempted to commit suicide.

6c. Do people who have attempted to commit suicide have a lower subjective quality of life or are they less well-adjusted than people who have not attempted to commit suicide?

Findings:

⇨ Those brain injured people who had (reportedly) attempted to commit suicide in the past were not less satisfied with their life nor were they any less well-adjusted (in terms of depression, anxiety, self-esteem, and acceptance of limitations) at the time of interview than those who had not attempted to commit suicide.

7.a. Do severely brain injured people and their carers report positive effects of their accident?

Findings:

⇨ Brain injured people reported significantly more positive effects from the traumatic brain injury than their carers (80% versus 37.9%);

7b. If so, what is the nature of such reported effects?

Findings:

⇨ Brain injured people reported positive effects in terms of changes in self-perception, understanding social relations, and life orientation

7c. What is the relationship between reported positive consequences on the one hand, and level of adjustment and subjective well-being on the other hand?

Findings:

⇨ Those who claimed to have learnt from the experience did not rate themselves as more satisfied and were not better adjusted than those who did not report such consequences.

11.4. DISCUSSION AND INTERPRETATION OF THE RESULTS

11.4.1. General Discussion

11.4.1.1. METHODOLOGICAL LIMITATIONS OF THE STUDY

It is important to take into account some of the limitations of this study when evaluating the results, although it is worth noting that some of the limitations outlined here are not necessarily unique to this study.

A limitation of this study was the fact that self-report data were used. The reason why this may be a limitation is that the researcher has no control over how the individuals in the research interpret the questions asked. For example, one person's interpretation of the word 'satisfied' may be very different from someone else's.

Random error may also have increased as a result of the topic of the study. Individuals were required to report on their own subjective status. The possibility of confusion over concepts, and the variation in the interpretation of what was required are clearly higher when the individual is required to report his subjective quality of life than, for example, when the participant is asked about his employment status.

Another limitation of this study was that it was cross-sectional. Results were therefore based on correlations between variables. This is something Diener et al. (1999) flag up as one of the main methodological shortcomings in the field of subjective well-being. They stated that: "*This shortcoming leaves researchers in an uncertain position regarding the causal priority of the variables they study"* (pp. 277). It is therefore impossible to draw strong conclusions on the causal link between variables in this study. However, it is unlikely that objective health status, as measured by post traumatic amnesia can be influenced by subjective factors. In this case the causal link is therefore likely to be uni-directional.

All patients recruited came from only three sources: Drs Freda Newcombe and Neil Brooks and several local Headway Houses. Furthermore, 26 Out of the total sample of 49 had been assessed for medico-legal purposes. The study did not look at a consecutive series of brain injured people. The sample is therefore not completely representative of the population of brain injured people.

Furthermore, the small sample size and possible selection bias in the case of the *control group*, which had a response rate of 51.5%, may limit the study. The nature of the research limits the sample to those who are willing to participate. In the case of the brain injured sample, the response rate was 90%, which is clearly very high, and may reflect the need of brain injured people and their carers to talk about their experiences.

Also with regard to the control group, the study would have benefited from more questionnaires filled in by the control group. The control group only filled in measures of satisfaction, the Future Expectations Scale and the Life Priority Scale. It would have been useful if other measures of adjustment (self-esteem, anxiety and depression) had been added.

It would also have been useful to know to what extent changes in terms of one's perception of the past are 'normal' developments, and to what extent they are part of having suffered a head injury. It would therefore have been useful to try to ask the control group to compare their present life with their life 7.6 years ago (7.6 years being the average time post-injury in the brain injured group) and to ask the brain injured group the same kind of questions.

Unfortunately, the design of the study did not allow for the use of too many questionnaires to be filled in by the control group. The control group was recruited by post and in the local Job Centre.

It was felt that the response rate would have been negatively affected had the time it took to fill in the questionnaires exceeded 20 minutes.

There was a clear selection bias, in the sense that only men between 18 and 40 took part in the study. It also excluded brain injured people who could not communicate or verbalise their thought and emotions.

The research would have benefited from more consistency in the administration of the questionnaires. Most questionnaires were filled in with the interviewer present, some were filled in when the interviewer had left, and some questionnaires were filled in by people who were not interviewed at all.

Three different clinicians estimated post-traumatic amnesia retrospectively. On the one hand, it can be argued that both Dr. FN and Dr. NB are much more experienced than the researcher in terms of estimating PTA. Also, their estimates of PTA had been done earlier in time and therefore closer to the accident. Both factors argue in favour of using their estimates of PTA, rather than using the researcher's estimates. On the other hand, using other clinician's estimates of PTA (rather than one's own) also raises major methodological issues. In particular, it is not clear whether the method used by the researcher is exactly the same as the ones used by Drs. FN and NB. This fact clearly decreases the reliability and validity of the PTA estimates and makes all the findings derived from the use of estimates of PTA less reliable.

In future research, different methods may be considered to increase the validity and reliability of the research. For example, experience sampling (sampling people's moods at random moments in respondents everyday lives) is thought to reduce memory biases that affect retrospective reports of experiences (Diener et al., 1999). Also, to increase the validity of self-report data, *triangulation* could be used, i.e. using different methods of measuring subjective quality of life (including experience sampling, recording memories for good and bad events, measuring reactions to emotionally ambiguous stimuli) and describing the common elements from the results of different methods. Furthermore, longitudinal research (following brain injured people from the time of the traumatic brain injury onwards) could clarify the exact course of adjustment following a severe

traumatic brain injury and should resolve some of the difficulties of cross-sectional research (i.e. problems of causality).

11.4.1.2. THE ROLE OF COGNITIVE FACTORS IN SUBJECTIVE JUDGEMENTS

Ratings of satisfaction are often seen as cognitive judgements, assessments of the general state one's life is in (Diener, 1993; Argyle and Martin, 1991; Diener et al., 1999). Diener (1993) stated that "*subjects must consult working and/or long-term memory and construct their report based on the material in consciousness*" (pp. 128). Participants must understand the question posed to them, search their memory, and select a response. Given the fact that brain injured people often have cognitive impairments (and having cognitive impairments was one of the inclusion criteria for this study), the question arises how this may have affected their judgements.

There is evidence that a number of factors play a role in judgements of satisfaction.
Firstly, people seem to judge their life satisfaction in terms of the most recent and most salient information available to them (e.g. Schwarz and Strack, 1991). One determinant is therefore the frequency and the recency with which the information was used. Schwarz and Strack (1991) found that people who had been induced to think about positive aspects of their life described themselves as happier than individuals who had been induced to think about negative aspects.
Furthermore, judgements of life satisfaction are also dependent upon current mood (because it increases the accessibility of mood congruent information), interview situation (e.g. people say they are more satisfied with their life when an attractive interviewer asks than when an unattractive interviewer asks; Schwarz and Strack, 1991), and social desirability.
Given these personal and situational temporary influences on judgements of satisfaction, it is surprising that the temporal stability of satisfaction judgements is as high as it is (Diener, 1999).

Schwarz and Strack (1991) showed that individuals rely more on mood information if their mood is pronounced, but use other salient information about their life in the absence of pronounced mood states[1]. Applied to this study, this implies that both brain injured people and the controls who were either in a very good mood state or in a very bad mood state (i.e. those who felt either

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[1] "When no pronounced mood state was induced, recalling negative past events resulted in reports of higher general well-being than recalling positive past events, thus showing contrast effects. When the recall task did include a pronounced mood state...mood had an overriding effect.

very happy or very down/depressed) when they were interviewed and filling in the questionnaires may have used their current mood information more than current and past cognitive information to judge their current level of subjective well-being. This process does not require the individual to sift through memory, and to select and compare experiences, but draws more on the ability to recognise current and past moods. This is not necessarily a problem, given the fact that current mood is highly correlated with more long-term aspects of well-being (Diener, 1993).

Although recognising one's own mood is usually not a problem for brain injured people, there are indications that 'reading' one's own emotional state is impaired after specific frontal lobe damage (Damasio, 1994).

Diener (1993) suggested that "*one way to obtain memories which accurately represent the person's life is to lead respondents through a life review before presenting the well-being questions*" (pp. 129). Such a review would decrease the possibility that one salient experience dominated the judgement of the individual regarding his level of satisfaction. This is exactly what happened in the current study: patients were interviewed regarding their perceptions of their situation, how they have experienced the recovery, etcetera. Only after being interviewed were they asked to fill in the questionnaires. This is likely to have increased the availability of memories on which brain injured people were then able to base their judgements of their own levels of satisfaction.

To summarise, brain injured people may not have the same collection of memories (post-injury) available as the controls, and may lack some of the cognitive skills necessary to judge satisfaction compared to the controls. Both the brain injured people and the controls may have relied on their mood as the main factor in judging their current level of well-being when their mood was pronounced. On the plus side, a life review prior to giving the questionnaire should have decreased the reliance on only a couple of salient experiences dominating the judgement of subjective quality of life.

One finding (section 7.4.) in this study increased the reliability (whether what they have rated is actually an accurate reflection of their own domain-specific satisfaction) and validity (whether they have actually rated 'domain-specific satisfaction') of the self-reports by brain injured people dramatically: the fact that the carers rated the brain injured person's domain-specific life satisfaction as exactly the same as the brain injured people themselves. This shows that the

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In that case, rticipants who described negative past events reported lower well-being than participants who described positive past events, replicating the mood effects found in other studies" (pp. 41)

conclusions the significant others have drawn from the brain injured person's communications, behaviour and feelings were the same as the conclusions the brain injured person drew from his own cognitions, behaviour and feelings. A third party therefore corroborated the brain injured person's own judgements, and therefore the reliability and validity of his self-reports. If the ratings of both the brain injured person and his significant other were similar in terms of their domain-specific life satisfaction, then it can be assumed that they would also be similar in terms of his global satisfaction. The brain injured person's self-report of his subjective quality of life can therefore be treated as a relatively accurate description of his subjective situation, *irrespective of his relative lack of memories post-injury, and irrespective of his cognitive impairments.*

11.4.2. Global and domain-specific subjective quality of life

The fact that brain injured people did not rate themselves any lower than a control group in terms of global satisfaction, is a finding that has been frequently reported in the literature (e.g. Schulz and Decker, 1985; Tempelaar et al., 1989; VanderZee at al., 1996). The same result was found in the present group of brain injured people.

Almost all the research comparing an 'ill' group with a control group has looked at more global aspects of subjective quality of life. This study tried to determine more exactly the domains brain injured people are dissatisfied about. The study found that brain injured people rated themselves significantly less satisfied than the control group in two domains (sexual life, mental abilities), and equally satisfied in 14 domains.
Why were these domains particularly affected?

Brain injured people without a partner were more unhappy about the fact that they did not have a partner than any other domain. At the same time, brain injured people were significantly more pessimistic than the controls about whether they would have a relationship with a partner in five years from now on the Future Expectations Scale. The mean score of the brain injured group to the question 'Do you think you will have a relationship with a partner in five years from now?' was 3.11, i.e. between 'maybe' and 'maybe not', whereas the mean score of the control group was 1.94, i.e. between 'definitely' and 'maybe' on the future Expectations Scale. This may go some way towards explaining the difference between brain injured people and controls in terms

of how satisfied they were about not having a partner: they haven't got a partner now, and they do not think they will have one in the future either.

Brain injured people were also significantly more dissatisfied about their sexual life than the control group. As explained in section 7.3.2., the difference between the two groups was completely due to the brain injured people who did not have a partner. Brain injured people with a partner were as satisfied with their sexual life as the controls with a partner. However, brain injured people without a partner were significantly more dissatisfied with their sexual life than the controls without a partner. Again, brain injured people were significantly more pessimistic about whether they would have a sexual life in five years time than the control group.

Overall, it would therefore seem that 'not having a partner' was even worse for a brain injured person than it is for someone who is not brain injured. There may be a number of explanations for this:

Firstly, they did not expect to have a partner in five years from now. This may have been for several reasons, e.g. mental or physical disabilities, changes in personality, stigmatisation of people with disabilities, or feelings of defectiveness. Qualitative research into this area would shed more light on this issue.

Secondly, they were more dissatisfied about their sexual life than the controls without a partner. Sexual experiences may be an important factor in this relatively young, masculine sample. A lack of a relationship, and the lack of a prospect of a relationship may have led to dissatisfaction with sexual life, which in turn may have led to dissatisfaction with the lack of a relationship.

From these two results (i.e. dissatisfaction with sexual life and not having a partner), it would also appear that having a partner was very significant for people with a traumatic brain injury. This was confirmed by the fact that those brain injured people with a partner expressed a higher subjective quality of life than the brain injured people without a partner. Brain injured people with and without a partner did not differ in terms of any other measure of adjustment. Having a partner has often been related to a higher degree of satisfaction in life (e.g. Argyle, 1987). This was confirmed by the fact that the controls with a partner also had a higher subjective quality of life than the controls without a partner.

Table 11.1. Domains which brain injured people were less satisfied about, and equally satisfied about compared to the control group

Significant difference	No significant difference
Mental abilities	Ability to take care of oneself
Sexual Life	The way days are spent
	Family life
	Life with partner
	Religious life
	Work situation
	Aims and purposes
	Friendships
	Physical abilities
	Satisfaction with oneself
	Not having a partner
	Leisure activities
	Independence

Brain injured people were also significantly more dissatisfied than the controls in terms of their 'mental abilities'. The reason is obvious. A traumatic brain injury may have a number of 'mental' consequences that the controls did not suffer from. A weakness of the question about mental abilities is that much variability is possible in the interpretation of this question. For some people 'mental abilities' may have referred to the cognitive effects of the traumatic brain injury, while for others it may refer more to the emotional state they were in. If it was interpreted as the former, it was still not clear which cognitive effects they were particularly dissatisfied about.

The next question is why brain injured people said they were equally satisfied with their life as a whole as the controls did, but clearly rated themselves less satisfied on certain domains. Why did unhappiness in separate domains not affect global satisfaction? There are two possible explanations for this.

Firstly, it is possible that global satisfaction is less dependent upon those domains that the brain injured sample has rated as less positive than the controls, and more upon other variables. Put differently: these domains are not very important to the person anyway. This is not very likely, looking at the correlation matrix in appendix 11.1. It shows that the two domains on which brain

injured people and controls differed were not particularly less correlated with subjective quality of life than the other domains.

The second possibility is that brain injured people have 'compartmentalised' their dissatisfaction, and do not allow it to affect their overall judgement of their lives. Effectively, this would mean that brain injured people are very much aware of the areas in their life they are dissatisfied about, but do not allow it to spill over into the rest of their life.

Adaptation-level theories of happiness predict that extreme levels of happiness and unhappiness wear off, and are contingent upon change (see section 4.6.). It would seem that some of the results found in this study confirm that this is the case: the fact that brain injured people and controls did not differ in terms of their global subjective quality of life and in terms of 14/16 domains of satisfaction. Nevertheless, the fact that brain injured people who were on average more than seven years post-injury still reported relative dissatisfaction in five out of sixteen domains of their life is contrary to what adaptation levels of subjective quality of life predict. Why was this the case?

Diener et al. (1999) and Loewenstein and Frederick (1999) both reported that, although adaptation can explain much of the subjective recovery following illness, it is often not sufficient. Section 4.7. cited a number of studies in which people did not adapt fully after loss or after illness. Diener et al. (1999) stated that there is "*considerable evidence that contradicts the .....theory that people completely and rapidly adapt to all circumstances*" (pp. 286). Loewenstein and Frederick (1999) pointed out that there are conditions to which people simply do not adapt, for example 'the pleasures of eating' and the avoidance of noise. This idea – that it may be impossible to adapt to certain conditions for some people may be applicable to the results found in this thesis. For example, it may be very difficult to adapt to not having a partner, not having the prospect of a partner in the future, not having a sexual life (nor having the prospect of an active sexual life in the future), and having reduced mental abilities. Why it would be that it is more difficult to adapt to these areas than it is to adapt to others is a matter for future research.

There may be a number of reasons why the had-injured group did not adapt completely to the effects of traumatic brain injury.

Firstly, it may be that it is difficult to adapt *to specific functional consequences* of loss or illness. This is quite likely, given the fact that brain injured people were equally satisfied about some domains, but not about others.

Secondly, it may be that adjustment to certain consequences is difficult *for certain people.* It may be that for some people the cognitive and emotional restructuring that is required in adaptation is difficult to achieve. It is likely that there is individual variation in the extent to which people are able to adapt. This was clearly witnessed by the researcher during the project. Some people appeared only to take a couple of days to adapt, whereas others were still not able to cope after 10 years. An interesting idea in this respect was put forward by Eisenberg, Fabes, Murphy, Maszk, Smith, and Karbon (1995), who suggested that children with a greater ability at 'emotion regulation' are able to adapt more quickly. This resonates with Diener et al. (1999) who thought that one of the major goals for the future in the field of subjective well-being research is: "*How does personality affect one's tendency to adapt to negative events?*" (pp. 286). There may therefore be something about certain people which allows them to adapt quickly to changes. What may be required is not so much more knowledge on *how* people adapt to the consequences of a traumatic brain injury (that was hopefully answered in this thesis; see the next section), but also particularly *who* adapts and *under what circumstances.* The latter refers to possible buffering influences, such as social support and work.

11.4.3. Adaptive Tasks and Subjective Quality of Life

Adaptation or habituation is a central component to modern theories of subjective well-being and adaptation is often hypothesised to mediate between objective health status and subjective quality of life (Diener et al., 1999). This was also one of the hypotheses to be tested in this study. We have already seen that brain injured people do seem to be able to adapt to the consequences of a traumatic brain injury in terms of their global subjective quality of life and in terms of 14 out of the 16 domains of satisfaction, but also that brain injured people had not adjusted fully in terms of 2 out of the 16 domains of satisfaction. This section will look more closely at the specific adaptive tasks that were hypothesised to mediate between objective health status and subjective quality of life. In the definition of adjustment taken in this project, people need to restructure their thoughts about the stimulus and its effect on their lives in three separate, but intimately connected tasks: becoming

aware of the impact of the limitations on their life, accepting the limitations, and starting to look forward again towards the reorganisation of their life. These three 'adaptive tasks' will be discussed below.

Awareness

The overall awareness score correlated significantly with post-traumatic amnesia (r = .35; p = .027; one-tailed). The fact that these relationships were found (which would normally be expected) increases the trustworthiness of the awareness score. Trudel, Tryon, and Purdum (1998) also found that their measure of lack of awareness (which was quantified as the difference between self-ratings and staff-ratings on scales of independent behaviour) was significantly related to post traumatic amnesia.

One of the most obvious criticisms of the findings in the current study goes as follows:
Participants who have suffered a very severe traumatic brain injury have more cognitive problems, and are also more likely to be less aware of the consequences. Because they are less aware, they feel fairly satisfied about their life. This is why post traumatic amnesia is not significantly correlated with subjective quality of life.
Only part of this argument is true. Severity of the injury was indeed positively correlated with awareness (r = 0.34). It was therefore true that the more severe the traumatic brain injury was, the less aware he was about the consequences of the accident. What was not true, however, was that brain injured people who lacked awareness were more satisfied with their life. This is one of the more remarkable findings of the study. The correlation between lack of awareness and global satisfaction was only 0.16. The reason for the relatively low correlation is twofold. Firstly, there were participants who lacked awareness, and were unhappy. This appeared to be because they found themselves in situations they could not understand, or found that people behaved in ways towards them they could not understand.
Secondly, there were brain injured participants who were aware and happy. This appeared to be because, despite the fact they are aware of their problems, they managed to incorporate their limitations into their perception of self, and they had become part of the 'new self'. In short, they had accepted their limitations.
Because of these two scenarios, the rule that 'unawareness means happiness and awareness means unhappiness' does not hold true.

Acceptance

Acceptance was shown to be relatively highly correlated with subjective quality of life and adjustment. Furthermore, it was also the only measure that was also significantly correlated with injury-related variables such as carer-perceived neurobehavioural problems and patient-perceived neurobehavioural problems ($r = -.60$ and $r = -.66$). More impairments therefore lead to less acceptance, and less acceptance is related to less global satisfaction. It would therefore seem to be a central spill in the relationship between impairments on the one hand and subjective quality of life on the other hand. A similar, central role for 'acceptance of limitations' was found in the research by Dodds et al. (1991), Hogg et al. (1994), and by MacCarthy and Brown (1989) in Parkinson's disease. In their research, acceptance was also related to both injury-related variables and to other adjustment variables.

It also indicates that the measure of acceptance of limitations used in the current study is the most sensitive measure used in this study. It therefore deserves more attention from clinicians in the rehabilitation of the severely brain injured person.

Three conceptual points regarding acceptance of limitations.

First, self-acceptance has been found to be highly correlated with subjective well-being (Ryff and Keyes, 1995). It could be argued that self-acceptance and acceptance of limitations are one and the same. This is, however, not true. Acceptance of limitations comes over and above acceptance of self. Limitations as a result of a traumatic brain injury come on top of all the things the person may not have liked about himself in the first place.

Secondly, a distinction can be made between 'cognitive acceptance' and 'emotional acceptance' (e.g. Parkes and Weiss, 1983). Cognitive acceptance involves recognition of the fact that there is a gap between the old and the new self, and thinking that the gap has been bridged. Emotional acceptance involves the lack of negative feelings about the accident and its consequences.

The 'acceptance of limitations scale' appears to tap more into the cognitive component of acceptance than the emotional component. Future research should determine firstly, if there is a

difference between the two, secondly, what exactly the difference is, and thirdly, what the determinant are of both types of acceptance.

Thirdly, in the current study, 'acceptance of limitations' has been treated as a single unitary concept. This may, however, not be the case. It is highly likely that some changes in the brain injured individual's life are more difficult to accept than other changes. Future research is needed to explore which changes are perceived to be more difficult to accept than others by the brain injured individual.

Past-future Orientation

One of the most striking results found in this study is the fact that brain injured people who look towards the past have a lower subjective well-being than brain injured people who do not do so. This result was not found in the control group. The question arises why this was the case.

Firstly brain injured people have a clear and obvious reference point to compare their present situation with. It can be assumed that most people in the control group have not experienced such a sudden event which has changed their life completely.

Furthermore memory deficits following the traumatic brain injury may play a role as well. Most brain injured people have anterograde memory problems, which means that they can remember the distant past before the accident very well, but have difficulties with memories since the accident. For the controls, memory of the past is much more continuous because they can remember both distant and more recent events.

Contrast effects, as described in section 4.6.3., were found in this study. In particular, it was found that brain injured people who often thought about their life before the accident had a lower subjective quality of life brain injured people who did not do so. The most likely explanation of this effect, is that the participant's present, less fortunate situation is contrasted with a 'glorious past', in which the participant did not suffer any impairments, disabilities, or handicaps.
Tversky and Griffin (1991) suggested that happiness can be maximised by "*treating positive experiences as endowments and negative experiences as contrasts*" (pp. 103). Brain injured people who often thought about the state they were in directly after the accident, should therefore have a higher subjective quality of life than those who did not do so. This study has confirmed that this is

partly the case. Thinking about life directly after the accident was related to level of acceptance of limitations, but not to any other measures of well-being or adjustment. However, this would appear to be partly the result of the low number of participants. Many brain injured people said they could not remember what they were like directly after the accident, and therefore could not answer the question.

The contrast effects found in this study therefore have to be treated with caution as a result of the low number of people who were able to answer this question. Further research is therefore required to confirm these results.

11.4.4. Predicting Subjective Quality of Life

The need for more information on predictors of quality of life was formulated by Murrell: "*At the present time, important predictors of quality of life in neurological illness and their paths of influence remain largely unclear*" (Murrell, 1999; pp. 227). The current research has given more information on the prediction of subjective quality of life. It has become clear that objective factors were not very good predictors of subjective quality of life. Furthermore, the best predictors of subjective quality of life were self-perceived neurobehavioural problems, acceptance of limitations, and past-future orientation.

This research has confirmed previously found results, namely that objective factors are not very good predictors of subjective well-being. Why is this the case?

Fuhrer et al. (1992), after failing to find a relationship between severity of injury and life satisfaction in a sample of people with spinal cord injury, suggested that because life satisfaction is far away in the causal flow of the WHO model from impairments, weaker associations would be expected. This may provide an explanation at a theoretical level, but does not actually explain the processes responsible for the weak link.

Traditional coping models (as proposed by Lazarus and Folkman, 1984; Lazarus, 1993) provide better answers. Coping models always invoke a process of 'primary appraisal' in order to determine "a threat to oneself" (Carver et al., 1989; pp. 267). Secondary appraisal concerns the perception of 'loss, threat, and challenge' (Sarafino, 1990).

Lazarus' and Folkman's model suggests that the appraisal the person makes of a threatening event is central to adjustment, because, as was already discussed in chapter two, a life event cannot be a crisis until it is considered as such by the victim. The extent to which an event is considered a crisis is determined by a number of antecedents, including personal resources (defined as the *"relatively stable characteristics that enable some individuals to resist the deleterious effects of stress, and adjust effortlessly across a range of situations"* (Menaghan, 1983; in Kendall and Terry, 1996)), environmental sources (e.g. social support), and situational factors.

Within the appraisal approach distress is not a function of objective characteristics of the situation, but of the subjective perception of the situation. It can therefore account for the following phenomena found in this study:

1. The fact that an objective measures of pathology and impairment (post traumatic amnesia) was unrelated to subjective quality of life and adjustment
2. The fact that self-perceived neurobehavioural problems were not significantly related to the severity of the injury.
3. The fact that self-perceived neurobehavioural problems were significantly more related to subjective well-being and adjustment than carer-perceived neurobehavioural problems, and post traumatic amnesia
4. The fact that brain injured people who perceived a gap between the old and the new self, and who had not been able to incorporate limitations into their new perception of self (i.e. had not accepted their limitations) experienced a lower subjective quality of life than people who had accepted their limitations.

11.4.5. A Summary: Subjective Quality of Life and its predictors

Overall, it would seem that brain injured people had managed to adapt very well to the long-term consequences of their traumatic brain injury. They experienced the same global subjective quality of life as a matched control group, and scored similarly in terms of 14 out of 16 domains of satisfaction. It would also seem that a number of adaptive tasks are highly related to this outcome, including the way the patient perceived his own problems, whether he had incorporated his limitations into his new perception of himself, and whether he no longer compared his

present situation to his pre-injury past. At the same time, the patient's objective health status in terms of his post traumatic amnesia was not related to subjective quality of life at all.

However, brain injured people did not adjust in all life domains, particularly not in terms of leisure activities, mental abilities, level of independence, sexual life, and not having a partner. It was suggested that future research should not just focus on *how* people adapt (one of the main foci of this thesis), but also on *who* adapts *under what kind of circumstances.*

11.4.6. Positive Consequences of a severe Traumatic Brain Injury

This study also considered whether brain injured people reported positive consequences from the experience of having had a traumatic brain injury. The rationale behind this was firstly a predominant focus in the literature on the negative effects of traumatic brain injury, as opposed to possible positive effects. Secondly, the subjective approach to measuring outcome and adjustment taken in this project made it possible to ask questions of this nature. Thirdly, being able to see positive effects of an event that inevitably has many negative consequences may be an important aspect in the adjustment process.

This study found that significantly more brain injured people than carers thought that positive consequences had followed the accident. There are a number of possible explanations for this finding.

Firstly, brain injured people may have felt compelled to paint a rosier picture of their life than was actually the case.

Secondly, the significant others may have felt not much positive has come out of the whole experience because they compared the brain injured person's present situation to the way he was before the accident. Given the extreme contrast, they may not have been able to detect anything positive.

Thirdly, brain injured people may have used 'seeing the positive side of things' as a coping mechanism, unlike their significant others.

It was striking that in a number of cases, both the brain injured person, and the carer indicated that there had been a change for the positive in the person's personality. These were mainly

cases in which the brain injured person was going off the rails before the accident, and the traumatic brain injury had made him more placid.

It was also found that brain injured people who felt they had learned more about life in general, other people, or themselves did not rate themselves as significantly more satisfied and were not better adjusted than brain injured people who did not report such consequences. Lehman et al. (1993) also found this result. There are a number of possible explanations for this finding.
Firstly, reports of 'learning effects' may be 'defensive illusions (Lehman et al., 1993), i.e. Some brain injured people may have tried to convince themselves that positive changes had occurred when, in fact, they had not.
Secondly, instead of trying to convince themselves that positive effects had occurred, some brain injured people may have tried to convince others, i.e. they may have tried to paint a rosier picture than was actually the case.

Overall, the conclusion appears to be that brain injured people did report positive consequences after their accident, but that reporting such consequences was not relevant in terms of their subjective status and adjustment. 'Trying to see the good that has come out of it' may therefore not be a useful therapeutic technique when counselling the brain injured person.

11.4.7. Suicide

Suicide and suicidal ideation is an issue which has not received the attention it deserves in the traumatic brain injury literature. Klonoff and Lage (1995) complained that they did not find studies or reports involving suicide risk or suicide rate during the rehabilitation process. In the current study, an attempt was made to estimate the percentage of brain injured people who claimed to have attempted suicide. Suicide was studied because it can, for obvious reasons, be considered a marker of bad subjective outcome and adjustment to the consequences of a traumatic brain injury.

Twenty five percent of all brain injured participants and 30.8% of all carers said that the participant had made a suicide attempt. When both patient reports and carer reports were added together (i.e. either reported it), 35.5% appeared to have made a suicide attempt. A further 25%

of the brain injured sample claimed that they had seriously considered taking their own life. These numbers are high. Furthermore, these percentages do not, of course, include any future suicide attempts and suicidal ideation, and may therefore underestimate the real figures. For example, patient no 039 did not rule out trying to commit suicide again in the future (his parents and GP were aware of this).

One of the difficulties in trying to measure suicidal ideation and suicide attempts is one of definition. Often, a distinction is made between suicide attempts with or without intent (Core guide, 1998). But when does a suicide attempt reflect a serious wish to die? When a person has taken 10, 20, 50, or 100 paracetamol tablets? For example, one of the clients in the present sample said he had tried to commit suicide by banging his head on the pavement. The extent to which he was aware that this is not an efficient way to commit suicide was not clear. The subjective approach taken in this project demanded that patients (and their carers) were taken seriously when they claimed they had attempted to commit suicide. However, it is important when interpreting the results, to consider that patients may have differed in terms of their intent. In either case (low or high intent), psychiatric and psychological intervention is called for.

Klonoff and Lage (1995) described the risk factors for suicide for people with a traumatic brain injury. These are: a greater preponderance of young males with a history of drug and alcohol abuse, depression, profound feelings of hopelessness, helplessness and despair. Hopelessness is one of the main predictors of suicide (Core Guide, 1998). Furthermore, brain injured people have problems with impulsivity, rigidity, and isolation. Klonoff and Lage's own research suggested that out of a total of 14 patients who participated in their rehabilitation programme, two committed suicide, and 11 presented with suicidal ideation.

In the current study, it was found at the time of the interview that there was no difference between those who had attempted to commit suicide in the past and those who had not in terms of their subjective quality of life and adjustment. However, it was found that the two groups differed in terms of carer-perceived neurobehavioural problems. This is an encouraging result. It suggests that there may be injury-related factors that can predict whether a person is more at risk of attempting to commit suicide or not. This should be further explored in future research, particularly looking at the specific neurobehavioural problems which may be related to whether a person is likely to attempt to commit suicide.

Why did those who had attempted to commit suicide score lower than those who had not in terms of carer-perceived neurobehavioural problems, but not in terms of post traumatic amnesia, or patient-perceived neurobehavioural problems?

The means of the two groups differed in terms of post traumatic amnesia (75 days versus 50 days), but this difference did not reach significance because of the low number of people in each group.

However, it is not clear why self-perceived neurobehavioural problems did not distinguish between those who had and those who had not attempted to commit suicide. It may be that adjustment mediates between perception of problems and suicide attempts, but this is a matter that will have to be looked at in future research.

Those brain injured people who had attempted to commit suicide and those who had not did not differ in terms of subjective quality of life or any other measure of adjustment. There may be several explanations for this.

Firstly, it may be that the attempt to commit suicide alerted significant others and the health services who subsequently intervened to improve the person's subjective quality of life and adjustment to bring it level with other, non-suicidal patients in the sample.

Secondly, it may be that what differentiated those who did and those who did not attempt to commit suicide was not so much their level of adjustment, as a personal characteristic or a consequence of the traumatic brain injury. For example, an obvious possible difference between the two groups might their level of impulsivity. Impulsivity is often associated with an increased risk of suicide (Core Guide, 1998).

Future research will need to determine the mediators between suicide attempts and level of adjustment.

11.5. CLINICAL IMPLICATIONS

There are different points of view as to what rehabilitation should try to achieve. On the one hand, the purely medical model suggests that it should be aimed at restoration of function to the highest possible level, in particular impairments and disabilities (Viitaanen et al., 1988). This view does not take into account the fact that illness, and in particular chronic illness, creates a gap between the old and the new self.

At the other extreme there are people who think that "rehabilitation should ultimately be aimed at securing social well-being or life satisfaction for rehabilitees and those close to them (Fugl-Meyer et al., 1991).

Between these extremes there is of course a healthy middle ground: yes, attention should be given to subjective aspects of the recovery, **and** everything should be done to restore as many functions as possible. Practically, it may not be possible to adjust to the consequences of a traumatic brain injury until all the consequences are actually known. Because recovery is still possible, particularly in the first year after the accident, adjustment to those consequences will be difficult to achieve. It is difficult to adjust to circumstances that change every month. Long-term adjustment will therefore usually take place after other rehabilitative efforts, such as cognitive and functional rehabilitation.

This study has shown that impairments and disabilities create the *perception* of a gap between the old and the new self which many brain injured people find hard to overcome. The perception of a gap and the inability to break with the past lead to a lower subjective quality of life.

The conclusion that because objective impairments are not significantly related to global satisfaction less attention should be paid to subjective factors in the recovery would be quite wrong. In fact the opposite is true. The implication is that subjective quality of life can be increased *regardless of* objective impairments. Interventions to increase subjective quality of life should therefore, become part of the rehabilitation programme for severely brain injured people. This has already been done in many of the better known rehabilitation programmes (e.g. Ben-Yishay, 1985), but the scientific underpinning of the philosophy behind this programme has so far not been established completely. This study shows that a clear focus on adjustment could lead to direct improvements in subjective quality of life.

It was found in this study that self-perceived problems were related to subjective quality of life and adjustment. It was also found that a more objective measure (post traumatic amnesia) was not related to subjective quality of life and adjustment. Furthermore self-perceived problems were not related to more objective measures of the brain injured person's problems.

The implications of these results is that the brain injured person may perceive a problem as major, but in reality it is only a minor problem in terms of its severity. Similarly, a brain injured person may perceive only a minor problem where there is, in reality, a major problem.

One therapeutic goal in rehabilitation follows logically from the process described above. It is to match the brain injured person's perception of his situation to the objective reality. This means that some brain injured people should learn that their problems are less severe than they perceive them to be. If successful, it follows that the brain injured person's subjective quality of life and adjustment should follow his perception of his own situation, and should therefore subsequently improve.

Others should learn that their problems are more serious than they perceive them to be. If successful, their subjective quality of life and adjustment should decrease initially. However, in the longer term it may help the brain injured person because he has a more realistic perception of the severity of his problems, which may subsequently help him achieve a realistic perception of his possibilities.

However, one of the difficulties in matching the person's perception of his situation to the objective reality is the fact that subjective quality of life is determined by many idiosyncratic beliefs and expectations and that information about the relative severity of the injury may not be perceived as an important factor.

It was found in this project that it is beneficial for brain injured people to restructure their thoughts about the traumatic brain injury and its consequences and need to achieve three separate, but intimately connected goals: becoming aware of the impact of the limitations on their life, accepting the limitations, and starting to look forward again towards the reorganisation of their life. This kind of restructuring of thoughts is of course an explicitly stated goal of cognitive therapy, and this kind of intervention would therefore seem to be most useful.

One of the most striking results of this study is the high number of brain injured people and carers who reported suicide attempts. Despite some of the methodological difficulties (what is a suicide attempt with intent?), it is clear that it may be more prevalent than previously thought. One way of combating suicide attempts is by a regular monitoring of mood states, level of awareness, and level of adjustment. The most obvious route is through appointing a case manager who is in regular contact with the brain injured person and his family, and who can be contacted when crises occur.l.lm

11.6. FUTURE RESEARCH

There are a number of ways in which the research could progress from here.

Some of the topics for future research are obvious from the selection criteria for this study. The question then becomes whether the results found in this study extend to samples which meet other inclusion criteria. For example, *what* is the subjective quality of life of women and older people who have sustained a traumatic brain injury firstly compared to other brain injured participants, and secondly compared to controls. Furthermore, is there a difference between the very mild cases (e.g. PTA less than one hour), and the more moderate and severe cases.

In section 11.4.2. , it was argued that was is required is not just research into *how* brain injured people adjust to the consequences of their injury, but particularly also more research into *who* adapts (i.e. personality factors) and *under what circumstances* (including more specific cognitive/functional deficits and social factors).

It would certainly be worthwhile to investigate whether long-term subjective quality of life after a traumatic brain injury differs from long-term subjective quality of life and adjustment after other illnesses (such as spinal cord injury). This may provide an opportunity to separate general disease-specific and traumatic brain injury-specific factors in the adjustment process.

'Acceptance' was shown to be a central aspect of the adjustment process, being related to both injury-related variables, and to subjective quality of life and level of adjustment. The concept of 'acceptance of limitations' therefore deserves more analysis in relation to the effects of traumatic brain injury. For example, it may be the case that some aspects of a traumatic brain injury are more difficult to accept than others. Furthermore, a distinction should be made between cognitive acceptance, and emotional acceptance.

A very important future research topic is suicide attempts and suicidal ideation. It is quite important to replicate the findings in this study with regards the number of suicide attempts in a larger sample. In particular, the exact nature of the suicide attempt should be operationalised, a measure of suicidal intent is required, and research into the correlates of whether somebody attempts to commit suicide is needed.

BIBLIOGRAPHY

Aaronson, N.K. (1989). Quality of life assessment in clinical trials: Methodologic issues. *Controlled Clinical Trials, 10*, 195s-208s.

Aaronson, E., Wilson, T.D., & Akert, R.M. (1997). *Social Psychology*. New York: Longman.

Affleck,G. & Tennen, H. (1991). Social comparison and coping with major medical problems. In J. Suls & T.A. Willis (Eds.). *Social comparison: contemporary theory and research*, pp 369-394. Hillsdale, NJ: Erlbaum.

Affelck, G., Tennen, H., Pfeiffer, C., Fitfield, J., & Rowe, J. (1987). Downward comparison and coping with serious medical problems. American *Journal of Orthopsychiatry, 57*, 570-578.

Alberts, M.S., & Binder, L.M. (1991). Premorbid psychosocial factors that influence cognitive rehabilitation following traumatic brain injury. In J.S. Kreutzer and P.H. Wehman (Eds.) *Cognitive rehabilitation for persons with traumatic brain injury.* (pp. 95-103). Baltimore: Paul H. Brookes.

Albrecht, G.L. (1994). Subjective health assessment. In Jenkinson, C. (ed.) *Measuring health and medical outcomes.* London: University College Press.

Alfano, D.P., Neilson, P.M., & Fink, M.P. (1993). Long-term psychosocial adjustment following head or spinal cord injury. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology, 6*(2), 117-125.

Anderson, R. (1988). The quality of life of stroke patients and their carers. In: Anderson, R., & Bury, M. *Living with chronic illness. The experience of patients and their families.* London: Unwin Hyman (pp 15-42).

Argyle, M. (1987). *The Psychology of Happiness*. London: Routledge.

Argyle, M., & Martin, M. (1991). The psychological causes of happiness. In: Strack, F., Argyle, M., & Schwarz, N. *Subjective Well-being. An International Perspective.* Oxford: Pergamon Press.

Aspinwall L.G., & Taylor, S.E. (1993). Effects of social comparison, threat and self-esteem on affect, evaluation, and expected success. *Journal of Personality and Social Psychology, 64*, 708-722.

Baker, F., & Intagliate, J. (1982). Quality of life in the evaluation of community support systems: A review of the literature. *Evaluation and Program Planning, 5*, 69-75.

Baker, F., Curbow, B., & Wingard, J.R. (1992). Development of the Satisfaction with Life Domains Scale for Cancer. *Journal of Psychosocial Oncology, 10*(3), 75-90.

Beaumont, J.G., Connolly, S.A.V., & Rogers, M.J.C. (1999). Inpatient cognitive and behavioural rehabilitation: assessing the outcomes. *Neuropsychological Rehabilitation, 9*(3-4), 401-412.

Beaufait, D.W, Nelson, E.C., Landgraf, J.M., Hays, R.D., Kirk, J.W., Wasson, J.H., & Keller A. (1992). COOP measures of functional status. In M. Stewart, F. Tudiver, M.J. Bass, E.V. Dunn, P.G. Norton (Eds.) *Tools for primary care research*, London: Sage.

Becker, G. (1993). Continuity after a Stroke: Implications of Life-course Disruption in Old Age. *The Gerontologist, 33*(2), 148-158.

Bennett, T.L. (1987). Neuropsychological counselling of the adult with minor traumatic brain injury. *Cognitive Rehabilitation, 1*, 10-16.

Ben-Yishay, Y., Rattok, J., Lakin, P., Piasetsky, E.B., Ross, B., Silver, S., Zide, E., & Ezrachi, O. (1985). Neuropsychologic rehabilitation: quest for a holistic approach. *Seminars in Neurology, 5*(3), 252-259.

Ben-Yishay, Y. (1988). What rehabilitation means in terms of real-world functions. Invited address, National Head Injuriy Foundation, Seventh Annual Symposium, Atlanta, Nov 15-19.

Ben-Yishay, Y. (1996). Personal Communication.

Bergner, M., obbitt, R.A., Carter, W.B., Gilson, B.G. (1981). The Sickness Impact Profile: development and final revision f a health status measure. *Medical Care, 19,* 787-805.

Bigelow, D.A., Gareau, M.J., & Young, D.J. (1990). A quality of Life interview. *psychosocial Rehabilitation Journal, 14*(2).

Bigelow, D.A., McFarland, B.H., & Olson, M.M. (1991). Quality of community mental health program clients: validating a measure. *Community Health Journal, 27*(1), 43-55.

Bond, M. (1984). The psychiatry of closed traumatic brain injury. In N. Brooks (Ed.), *Closed traumatic brain injury. Psychological, social and family consequences* (pp. 148-178). London: Oxford University Press.

Bowlby, J. (1973). *Separation: anxiety and anger.* New York: Basic Books.

Bradburn, N.M. (1969). *The structure of psychological well-being.* Chicago: Aldine.

Branholm, I.B., Lundmark, P., Månsson, M., & Fugl-Meyer, A.R. (1996). On life satisfaction in subjects with neurological disorders. *Neurological Rehabilitation, 2,* 63-67.

Brickman, P., Coates, D., & Janoff-Bulman, R. (1978). Lottery winners and accident victims: is happiness relative? *Journal of Personality and Social Psychology, 36*(8), 917-927.

Brim, O.G., & Ryff, C.D. (1980). On the properties of life events. In P.B. Baltes and O.G. Brim (Eds.). *Life span development and behavior* (Vol.3). (pp. 28, 132, 136-137). New York: Academic Press.

Brooks, D.N., & McKinlay, W. (1983). Personality and behavioural change after severe blunt traumatic brain injury - a relative's view. *Journal of Neurology, Neurosurgery and Psychiatry, 46,* 336-344.

Brooks, N., Campsie, L., Symington, C., Beatie, A., & McKinlay, W. (1986). The five year outcome of severe blunt traumatic brain injury: a relative's view. *Journal of Neurology, Neurosurgery and Psychiatry, 49,* 764-770.

Brooks, N., Hosie, J., Bond, M.R., Jennett, B., & Aughton, M. (1986). Cognitive sequelae of severe traumatic brain injury in relation to the Glasgow Outcome Scale. *Journal of Neurology, Neurosurgery and Psychiatry, 49,* 549-553.

Brooks, N., Campsie, L., Symington, C., Beatie, A., & McKinlay, W. (1987). The effects of severe traumatic brain injury on patient and relative within seven years of injury. *Journal of Head Trauma Rehabilitation, 2*(3), 1-13.

Brooks, N., McKinlay, W., Symington, C., Beattie, A., & Campsie, L. (1987). Return to work within the first seven years of severe traumatic brain injury. *Brain Injury, 1*(1), 5-19.

Brooks, N. (1989). The brain injured family. *Journal of Clinical and Experimental Neuropsychology, 13*(1), 155-188.

Brooks, N. (1989). Defining outcome. *Brain Injury, 3*(4), 325-329.

Brooks, D.N. (1990). Cognitive deficits. In M. Rosenthal, E.R. Griffith, M.R. Bond, & J.D. Miller. *Rehabilitation of the Adult and Child with Traumatic Brain Injury.* Second Edition. (pp. 163-178). Philadelphia: F.A. Davis Company.

Brooks, N. (1991). The effectiveness of post-acute rehabilitation. *Brain Injury, 5*(2), 103-109.

Calman, K.C. (1984). Quality of Life in Cancer Patients - an Hypothesis. Journal of Medical Ethics, 10, 124-127.

Campbell, A., Converse, P.E., & Rogers, W.L. (1976). *The quality of American life.* New York: Sage.

Campbell, J.M. (1987). Patient's point of view. *Cognitive Rehabilitation, 1,* 24-25.

Canine, J.D. (1996). The psychosocial aspects of death and dying. Stamford, CN: Appleton and Lange.

Cannon, W. (1932). *The Wisdom of the Body.* New York: Norton.

Carver, C.S., Weintraub, J.K., & Scheier, M.F. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267-283.

Christensen, A.L., & Rosenberg, N.K. (1991). A critique of the role of psychotherapy in brain injury rehabilitation. *Journal of Head Trauma Rehabilitation, 6*(4), 56-61.

Cicerone, K.D. (1991). Psychotherapy after mild traumatic brain injury: relation to the nature and severity of subjective complaints. *Journal of Head Trauma Rehabilitation, 6*(4), 30-43.

Clegg, F. (1988). Bereavement. In: Fisher, S. and Reason, J. (Eds.). *Handbook of Life Stress, Cognition, and Health.* John Wiley and Sons Ltd.

Conkey, R.C. (1938). *Psychological changes associated with head injuries.* Archives of Psychology, No. 232. New York.

Cohen, L.H. (1988). Measurement of life events. In L.H. Cohen (Ed.). *Life Events and Psychological Functioning* (pp. 11-30). Newbury Park: Sage Publications.

Collins, R.L., Taylor, S.E., & Skokan, L.A. (1990). A better world or a shattered vision? Changes in life perspectives following victimization. *Social Cognition, 8*(3), 263-285.

Corrigan, J.D. (1989). Development of a scale for assessment of agitation following traumatic brain injury. *Journal of clinical and experimental Neuropsychology, 11*(2), 261-277.

Corrigan, J.D., & Bogner, J.A. (1994). Factor structure of the Agitated Behavior Scale. *Journal of Clinical and Experimental Psychology, 16*(3), 386-392.

Cramer, J.A. (1993). A clinimetric approach to assessing quality of life in epilepsy. *Epilepsia, 34*(suppl. 4), s8-s13.

Crisp, R. (1992). The long-term adjustment of 60 persons with spinal cord injury. *Australian Psychologist, 27*(1), 43-47.

Crisp, R. (1993). Personal responses to traumatic brain injury: a qualitative study. *Disability, Handicap and Society, 8*(4), 393-404.

Dana, E.R., Lalwani, N., & Duval, S. (1997). Objective self-awareness and focus of attention following awareness of self-standard discrepancies: changing self or changing standards of correctness. *Journal of Social and Clinical Psychology, 16*, 359-380.

Dann, M.D. (1984). From the patient's point of view. Loss of self. *The Journal of Cognitive Rehabilitation, 2*(6), 11

Davies, P., & Mehan, H. (1988). Professional and family understanding of impaired communication. *British Journal of Disorders of communication, 23*, 141-151.

Davies, P. (1995). Sociological approaches to health outcomes. In H. MacBeth (Ed.) *Health outcomes reviewed: biological and social aspects.* Oxford: Oxford University Press.

Davis, A., Davis, S., Moss, N., Marks, J., McGrath, J., Hovard, L., Axon, J., & Wade, D. (1992). First steps towards an interdisciplinary approach to rehabilitation. *Clinical Rehabilitation, 6*, 237-244.

Dean, S., Colantonio, A., Ratcliff, G., & Chase, S. (2000). Clients' perspectives on problems many years after traumatic brain injury. *Psychological reports, 86*, 653-658.

Dembo, T., Leviton, G.L., Wright, B.A. (1956). Adjustment to misfortune. A problem of social-psychological rehabilitation. *Artificial Limbs, 3*(2), 4-62.

Dembo, T., Leviton, G.L., & Wright, B.A. (1975). Adjustment to misfortune. A problem of social-psychological rehabilitation. *Rehabilitation Psychology, 22*(1). Special monograph issue.

Devinsky, O., & Cramer, J.A. (1993). Introduction: quality of life in epilepsy. *Epilepsia, 34*(suppl. 4), s1-s3.

Devinsky, O., & Penry, J.K. (1993). Quality of life in epilepsy: the clinician's view. *Epilepsia, 34*(suppl. 4), s4-s7.

Devinsky, O. (1993). Clinical uses of the quality-of-life in epilepsy inventory. *Epilepsia, 34*(Suppl.4), s39-s44.
Diener, E. (1984). Subjective well-being. *Psychological Bulletin, 95*(3), 542-575.

Diener, E. & Emmons, R.A. (1984). The independence of positive and negative affect. *Journal of Personality and Social Psychology, 47*, 1105-1117.

Diener, E., Emmons, R.A., Larsen, R.J., and Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment, 49*, 71-76.

Diener, E. (1994). Assessing subjective well-being: Progress and opportunities. *Social Indicators Research, 31*, 103-157.

Diener, E., Suh, E.M., Lucas, R.E., and Smith, H.L. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin, 125*(2), 276-302.

Dikmen, S., Machamer, J., & Temkin, N. (1993). Psychosocial outcome in patients with moderate to severe traumatic brain injury: 2-year follow-up. *Brain Injury, 7*(2), 113-124.

Dikmen, S.S., Ross, B.L., Machamer, J.E. & Temkin, N.R. (1995). One year psychosocial outcome in head injury. *Journal of the International neuropsychological society, 1*, 67-77.

Diller, L. (1994). Finding the right treatment combinations: changes in rehabilitation over the past five years. In A-L. Christensen, & B.P. Uzzell (Eds.). *Brain Injury and Neuropsychological Rehabilitation: International Perspectives.* (pp. 1-15). Hillsdale: Lawrence Erlbaum Associates.

Dodds, A.G., Bailey, P., Pearson, A., & Yates, L. (1991). Psychological factors in acquired visual impairment: The development of a scale of adjustment. *Journal of Visual Impairment and Blindness, 5, 306-310.*

Dodds, A.G., Flannigan, H., & Ng, L. (1993). The Nottingham Adjustment Scale: a validation study. *International Journal of Rehabilitation Research, 16*, 177-184.

Dodds, A., Ferguson, E., Ng, L., Flannigan, H., & Yates, L. (1994). The concept of adjustment: a structural model. *Journal of Visual Impairment and Blindness, 6*, 487-497.

Endicott, J., Nee, J., Harrison, W., & Blumenthal, R. (1993). Quality of life enjoyment and satisfaction questionnaire: a new measure. *Psychopharmacology Bulletin, 29*(2), 321-326.

Ezraki, O., Ben-Yishai, Y., Kay, T., Diller, L., & Rattok, J. (1991). Predicting employment in traumatic brain injury following neuropsychological rehabilitation. *Journal of Head Trauma Rehabilitation, 6*(3), 71-84.

Felton, B.J., & Revenson, T.A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. *Journal of Consulting and Clinical Psychology, 52*(3), 343-353.

Festinger, L.A. (1954). A theory of social comparison processes. *Human Relations, 7*, 117-140.

Festinger, L. (1957). *A theory of cognitive dissonance.* Stanford CA: Stanford University Press.

Filipp, S-H., & Klauer, Th. (1991). Subjective well-being in the face of critical life events: the case of successful copers. In: Strack, F., Argyle, M., & Schwarz, N. *Subjective well-being. An International perspective.* Oxford: Pergamon Press.

Filipp, S-H. (1992). Could it be worse? The diagnosis of cancer as a prototype of traumatic life events. In Montada, L., Filipp, S-H., & Lerner, M.J. (eds.). *Life crises and experiences of loss in adulthood.* Hillsdale: Lawrence Erlbaum Associates.

Fitzpatrick, R., Fletcher, S., Gore, S., Spiegelhalter, D., & Cox, D. (1992). Quality of life measures in health care. I: Applications and issues in assessment. *British Medical Journal, 305*, 1074-1077.

Fleming, J.M., Strong, J., & Ashton, R. (1996). Self-awareness of deficits in adults with traumatic brain injury: how best to measure? *Brain Injury, 10*(1), 1-15.

Fletcher, A., Gore, S., Jones, D., Fitzpatrick, R., Spiegelthaler, D., & Cox, D. (1992). Quality of life measures in health care. II: Design, analysis, and interpretation. *British Medical Journal, 305*, 1145-1148.

Franzoi, S.L. (2000). *Social Psychology*. Boston: McGraw-Hill.

Frey, D. (1991). Psychological factors related to the recuperation of accident victims. In F. Strack, M. Argyle, & N. Schwarz. *Subjective well-being. An International perspective.* (pp. 57-63). Oxford: Pergamon Press.

Fugl-Meyer, A.R., & Fugl-Meyer, K.S. (1988). The coping process after traumatic brain injury. *Scandinavian Journal of Rehabilitation Medicine,* Suppl 17, 51-53

Fugl-Meyer, A.R., Bränholm, I-R., and Fugl-Meyer, K.S. (1991). Happiness and domain-specific life satisfaction in adult northern Swedes. *Clinical Rehabilitation, 5,* 25-33.

Fuhrer, M.J., Rintala, D.H., Hart, K.A., Clearman, R., and Young, M.E. (1992). Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community. *Archives of Physical Medicine and Rehabilitation, 73,* 552-557.

Gilbert,D.T., Giesler, R.B., & Morris, K.A. (1995). When comparisons arise. *Journal of Personality and Social Psychology, 69,* 227-236.

Girard. V., & Schadelle, J.M. (1975). La personalité post-traumatique (The post-traumatic personality). *Revue de Médecine Psychosomatique, 18*(2), 135-156.

Glaser, B.G. and Strauss, A.L (1967). The discovery of grounded theory: strategies for qualitative research. Chicago: Aldine.

Godfrey, H.P.D., Partridge, F.M., Knight, R.G., & Bishara, S. (1993). Course of insight disorder and emotional dysfunction following closed traumatic brain injury: a controlled cross-sectional follow-up study. *Journal of Clinical and Experimental Neuropsychology, 15*(4), 503-515.

Goldstein, K. (1947; republished in 1995). Organismic approach to the problem of motivation. *Transactions of the New York Academy of Sciences. 9*(6), 218-230.

Goode, D.A. (1983). Who is Bobby? Ideology and method in the discovery of a Down's syndrome person's competence. In G. Kielhofner (Ed.). *Health through occupation.* Philadelphia: FA Davis Co.

Gordon, A. (1932). Delayed mental disorders following cranial traumatism and their psychpopathological interpretation.

Gouvier, W.D., Blanton, P.D., LaPorte, K.K., & Nepomuceno, C. (1987). Reliability and validity of the Disability Rating Scale and the Levels of Cognitive Functioning Scale in monitoring recovery from severe traumatic brain injury. *Archives of Physiological and Medical Rehabilitation, 68,* 94-97.

Guilford, J.P. (1965). *Fundamental Statistics in Psychology and Education.* McGraw-Hill Book Company: New York.

Hall, K.M., Hamilton, B.B., Gordon, W.A., & Zasler, N.D. (1993). Characteristics and comparisons of functional assessment indices: disability rating scale, FIM and FAM. *Journal of Head Trauma Rehabilitation, 8,* 60-74.

Harrell, M., & O'Hara, C.C. (1991). Meeting the emotional needs of brain injury survivors: an empowerment approach to psychotherapy. *Cognitive Rehabilitation, 9*(2), 12-15.

Hays, R.D., Anderson, R., & Revicki, D. (1993). Psychometric considerations in evaluating health-related quality of life measures. *Quality of life Research, 2*(5), 441-449.

Headey, B., & Wearing, A. (1989). Personality, life events, and subjective well-being: Toward a Dynamic Equilibrium Model. *Journal of Personality and Social Psychology, 57*(4), 731-739.

Heady, B., & Wearing, A. (1992). *Understanding happiness. A theory of subjective well-being.* Melbourne: longman Cheshire.

Heaton, R.K., Barth, J.T., Crosson, B.A., Larrabee, G.J., & Reynolds, C.R. (2002). Request for review papers on empirical support for areas of neuropsychological practice. *Newsletter 40* (Newsletter of the Division of Clinical Neuropsychological Practice), 20, 36-41.

Heyink, J. (1993). Adaptation and well-being. *Psychologichal Reports, 73,* 1331-1342.

Higgins, ET. (1987). Self-discrepancy: A theory relating self and affect. *Psychological review, 94*, 319-340.

Higgins, E.T., Roney, C.J.R., Crowe, E., & Hymes, C. (1994). Ideal versus ought predilections for approach and avoidance: Distinct self-regulatory systems. *Journal of Personality and Social Psychology, 66*, 276-286.

Hill, H. (1997). Re-inventing Identity. *Dulwich Centre Newsletter, 4*, 36-38.

Hogg, K.E., Goldstein, L.H., & Leigh, P.N. (1994). The psychological impact of motor neurone disease. *Psychological Medicine, 24*, 625-632.

Holosko, M.J., & Huege, S. (1989). Perceived social adjustment and social support among a sample of head injured adults. *Canadian Journal of Rehabilitation, 2*(3), 145-154.

Hoofien, D., Gilboa, A., Vakil, E., & Donovick, P.J. (2001). Traumatic brain injury 10-20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities, and psychosocial functioning. *Brain Injury, 15*(3), 189-209.

Horowitz, M.J. (1979). Psychological Response to Serious Life Events. In V. Hamilton, & D.M. Warburton (Eds.). *Human Stress and Cognition. An Information Processing Approach*, pp. 235-263. Chichester: John Wiley & Sons.

Hyland, M.E., & Kenyon, C.A.P. (1992). A measure of positive health-related quality of life: the satisfaction with illness scale. *Psychological Reports, 71*, 1137-1138.

Hyland, M.E. (1992). A reformulation of quality of life for medical science. *Quality of Life Research, 1*, 267-272.

Jackson, H.F., Hopewell, C.A., Glass, C.A., Warburg, R., Dewey, M., & Ghadiali, E. (1992). The Katz Adjustment Scale: modification for use with victims of traumatic brain and spinal injury. *Brain Injury, 6*(2), 109-127.

Jacobs. H.E. (1988). The Los Angeles Head Injury Survey: Procedures and intitial findings. *Archives of Physical Medicine and Rehabilitation, 69*, 425-431.

Jacobson, D.E. (1986). Types and timing of social support. *Journal of Health and Social Behaviour*, 27, 250-264.
Jacoby, A. (1992). Epilepsy and the quality of everyday life. *Social Science and Medicine, 34*(6), 657-666.

Janoff-Bulman, R., & Timko, C. (1987). Coping with traumatic life events. The role of denial in light of people's assumptive worlds. In C.R. Snyder, & C.E. Ford. *Coping With Negative Life Events.* (pp. 135-159). New York: Plenum Press.

Janoff-Bulman, R., & Schwartzberg, S.S. (1991). Toward a general model of personal change. In Snyder, C.R., & Forsyth, D.R. (Eds.). *Handbook of Social and Clinical Psychology* (pp. 488-508). New York: Pergamon Press.

Jenkinson, C. (1994). *Measuring health and medical outcomes.* London: University College Press.

Jennett, B., & Bond, M. (1975). Assessment of outcome after severe brain damage. *The Lancet, march 1*, 480-484.

Jennett, W.B., & MacMillan, R. (1981). Epidemiology of traumatic brain injury. *British Medical Journal, 282,* 101-107.

Jennett, B. (1990). Scale and scope of the problem. In M. Rosenthal, E.R. Griffith, M.R. Bond, & J.D. Miller. *Rehabilitation of the Adult and Child with Traumatic Brain Injury.* Second Edition. (pp. 3-7). Philadelphia: F.A. Davis Company.

Jennett, B. (1996). Epidemiology of traumatic brain injury. *Journal of Neurology, Neurosurgery, and Psychiatry, 60,* 362-369.

Jennett, B. (1998). Epidemiology of traumatic brain injury. (5), 403-406.Archives of Disease in Childhood, 78*(5) 403-406.*

Johnston, M. (1996). Models of disability. *The Psychologist,* 5, 205-210.

Kaitaro, T., Koskinen, S., & Kaipio, M.-L. (1995). Neuropsychological problems in everyday life: a 5-year follow-up study of young severely closed-brain injured patients. *Brain Injury, 9*(7), 713-727.

Kaplan, S.P. (1988). Adaptation following serious brain injury: an assessment after one year. Journal of Applied Rehabilitation Counseling, 19(3), 3-8.

Kaplan, S.P. (1991). Psychosocial adjustment three years after traumatic brain injury. The Clinical Neuropsychologist, 5(4), 360-369.

Katz, M.M. and Lyerly, S.B. (1963). Methods for measuring adjustment and social behaviour in the community: rationale, description, discriminative validity and scale development. *Psychological Reports, 13*, 503-535.

Keany, K.C.M-H., & Glueckauf, R.L. (1993). Disability and value change: An overview and reanalysis of acceptance of loss theory. *Rehabilitation Psychology, 38*(3), 199-210.

Keen, T. (1995). Traumatic brain injury, loss and grief. *Headway News,* Autumn, 13.

Kendall, E., and Terry, D.J. 1996. Psychosocial Adjustment Following Closed Traumatic brain injury: A Model for Understanding Individual Differences and Predicting Outcome. *Neuropsychological Rehabilitation, 6*(2), 101-132.

Klonoff, P.S., & Lage, G.A. (1995). Suicide in traumatically brain-injured patients: risk and prevention. *Barrow Neurological Institute Quarterly, 11*(4), 35-41.

Kolb, B. & Whishaw, I.Q. (1990). *Fundamentals of Human Neuropsychology.* Freeman and Company: New York.

Kozloff, R. (1987). Networks of social support and the outcome from severe traumatic brain injury. *Journal of Head Trauma Rehabilitation, 2*(3), 14-23.

Krause, J.S., & Sternberg, M. (1997). Ageing and adjustment after spinal cord injury: The roles of chronological age, time since injury, and environmental change. *Rehabilitation Psychology, 42,* 287-302.

Krause, J.S. (1997). Adjustment after spinal cord injury: A 9-year longitudinal study. *Archives of Physical Medicine and Rehabilitation, 78,* 651-657.

Kreutzer, J.S., Zasler, N.D. (1989). Psychosexual consequences of traumatic brain injury: methodology and preliminary findings. *Brain Injury, 3*(2), 177-186.

Kreutzer, J.S., Devany, C.W., Myers, S.L., & Marwitz, J.H. (1991). Neurobehavioral outcome following traumatic brain injury. Review, methodology, and implications for cognitive rehabilitation. In J.S. Kreutzer and P.H. Wehman (Eds.) *Cognitive rehabilitation for persons with traumatic brain injury.* Paul H. Brookes, Baltimore, MD.

Kreutzer, J.S., Gervasio, A.H., Camplair, P.S. (1994). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury, 8*(3), 211-230.

Kreutzer, J.S., Marwitz, J.H., & Witol, A.D. (1995). Interrelationships between crime, substance abuse, and aggressive behaviours among persons with traumatic brain injury. *Brain Injury, 9*(8), 757-768.

Kreutzer, J.S., Marwitz, J.H., Seel, R., & Devany Serio, C.(1996). Validation of a neurobehavioral functioning inventory for adults with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 77,* 116-124.

Kubler-Ross, E. (1969). *On death and dying.* New York: MacMillan.

Lazarus, R.S. (1993). Coping theory and research: past, present, and future. *Psychosomatic Medicine, 55,* 234-247.

Leach, L.R., Frank, R.G., Bouman, D.E., Farmer, J. (1994). Family functioning, social support and depression after traumatic brain injury. *Brain injury, 8*(7), 599-606.

Lehman, A.F., & Burns, B.J. (1990). Severe mental illness in the community. In Spilker, B. (Ed.). *Quality of life assessments in clinical trials.* New York: Raven Press.

Lehman, A.F., Postrado, L.T., & Rachuba, L.T. (1993). Covergent validation of life assessments for persons with severe mental illnesses. *Quality of Life Research, 2*(5), 327-333.

Lehman, D.R., Davis, C.G., Delongis, A., Wortman, C.B., Bluck, S., Mandel, D.R., & Ellard, J.H. (1993). Positive and negative life changes following bereavement and their relations to adjustment. *Journal of Social and Clinical Psychology, 12*(1), 90-112.

Lehman, D.R., Wortman, C.B., & Williams, C.F. (1987). Long-term effects of loosing a spouse or child in a motorcycle accident. *Journal of Personality and Social Psychology, 52*, 218-231.

Levin, H.S., High, W.M., Goethe, H.E., Sisson, R.A., Overall, J.E., Rhoades, H.M., Eisenberg, H.M., Kalisky, Z.V.I., Gary, H.E. (1987). The Neurobehavioral Rating Scale: assessment of the behavioral sequelae of traumatic brain injury by the clinician. *Journal of neurology, Neurosurgery and Psychiatry, 50*, 183-193.

Levin, H.S., Grossman, R.G., Rose, J.E., & Teasdale, G. (1979) Long-term neuropsychological outcome of closed traumatic brain injury. *Journal of Neurosurgery, 50*, 417-422.

Levin, H., & Kraus, M.F. (1994). The frontal lobes and traumatic brain injury. *The Journal of Neuropsychiatry and Clinical Neurosciences, 6*, 443-454.

Lewis, L. (1991). Role of psychological factors in disordered awareness. In: Levin, H.S., Eisenberg, H.M., & Benton, A.L. *Frontal lobe function and dysfunction.* New York: Oxford University Press, pp. 222-239.

Lewis, L. (1991). A framework for developing a psychotherapy treatment plan with brain injured patients. *Journal of Head Trauma Rehabilitation, 6*(4), 22-29.

Lezak M.D. (1978). Living with the characterologically altered brain-injured patient. *Journal of Clinical Psychiatry, 39*, 592-598.

Lezak, M.D., & O'Brien, K.P. (1988). Longitudinal study of emotional, social and physical changes after traumatic brain injury. *Journal of Learning Disabilities, 21*(8), 456-463.

Lezak, M.D. (1995). *Neuropsychological Assessment.* New York: Oxford University Press.

Linge, F.R. (1990). Faith, hope, and love: Non-traditional therapy in recovery from serious traumatic brain injury, a personal account. *Canadian Journal of Psychology, 44*(2), 116-129.

Linkowski, D.C. (1971). A scale to measure acceptance of disability. *Rehabilitation Counselling Bulletin, 14*, 236-244.

Linkowski, D.C., & Dunn, M.A. (1974). Self-concept and acceptance of disability. *Rehabilitation Counseling Bulletin*, September, 28-32.

Lishman, W.A. (1973). The psychiatric sequelae of traumatic brain injury: a review. *Psychological Medicine, 3*, 304-318.

Lishman, W.A. (1998). *Organic Psychiatry.* Oxford: Blackwell Science.

Livingston, M.G., Livingston, H.M. (1985). The Glasgow Assessment Schedule: clinical and research assessment of traumatic brain injury outcome. *International Rehabilitation Medicine, 7*, 145-149.

Livingston, M.G., Brooks, D.N., Bond, M.R. (1985). Patient outcome in the year following severe traumatic brain injury and relatives' psychiatric and social functioning. *Journal of Neurology, Neurosurgery and Psychiatry, 48*, 876-881.

Livneh, H. and Antonak, R.F. (1991). Temporal structure of adaptation to disability. *Rehabilitation Counseling Bulletin, 34*(4), 298-319.

Livneh, H. and Antonak, R.F. (1994). Psychosocial reactions to disability: a review and critique of the literature. *Critical Reviews in Physical and Rehabilitation Medicine, 6*(1), 1-100.

Loewenstein, G. & Frederick, S. (1999). Hedonic adaptation. In: Kahneman, Daniel (Ed); Diener, Ed (Ed); et al. (1999). *Well-being: The foundations of hedonic psychology.* (pp. 302-329). New York, NY, US: Russell Sage Foundation.

MacCarthy, B., & Brown, R. (1989). Psychosocial factors in Parkinson's disease. *British Journal of Clinical Psychology, 28*, 41-52.

Mahoney, F.I. & Barthel, D.W. (1965). Functional evaluation: The Barthel Index. *Maryland State Medical Journal, 14*, 61-65.

Malec, J.F., and Thompson, J.M. (1994). Relationship of the Mayo-Portland Adaptability Inventory to functional outcome and cognitive performance measures. *Journal of Head Trauma Rehabilitation, 9,* 116-124.

Malia, K., Powell, G., & Torode, S. (1995). Personality and psychosocial function after brain injury. *Brain Injury, 9*(7), 697-712.

Manchester, D. and Wood, R. Ll. (2002). Applying cognitive therapy in neurobehavioural rehabilitation. McMillan, T.M. and Wood, R. Ll. (2002). *Neurobehavioural disability and social handicap following traumatic brain injury.* Psychology Press: Hove

Masson, F., Vecsey, J., Salmi, L.R., Dartigues, J.F., Erny, Ph., & Maurette, P. (1997). Disability and handicap 5 years after a head injury: a population based study. *Journal of Clinical Epidemiology, 50*(5), 595-601.

McDowell, J., Newell, C. (1987). *Measuring health: a guide to rating scales and questionnaires.* New York, Oxford University Press.

McMillan, T.M., Jongen, E.L.M.M., & Greenwood, R.J. (1996). Assessment of post-traumatic amnesia after severe closed traumatic brain injury: retrospective or prospective? *Journal of Neurology, Neurosurgery, and Psychiatry, 60,* 422-427.

McMillan, T.M. and Sparkes, C. (1991). Goal planning and neurorehabilitation: The Wolfson Neurorehabilitation Centre Approach. *Neuropsychological Rehabilitation, 9*(3-4), 241-251.

McMillan, T.M. and Wood, R. Ll. (2002). *Neurobehavioural disability and social handicap following traumatic brain injury.* Psychology Press: Hove

McMillan, T.M. and Oddy, M. (2002). Service provision for social disability and handicap after acquired brain injury. In McMillan, T.M. and Wood, R. Ll. (2002). *Neurobehavioural disability and social handicap following traumatic brain injury.* Psychology Press: Hove

Melamed, S., Groswasser, Z., & Stern, M.J. (1992). Acceptance of disability, work involvement and subjective rehabilitation status of traumatic brain-injured (TBI) patients. *Brain Injury, 6*(3), 233-243.

Miller, H., & Stern, G. (1965). The long-term prognosis of severe traumatic brain injury. *The Lancet, 1,* 225-229.

Miller, L. (1993). *Psychotherapy of the brain-injured patient. Reclaiming the shattered self.* New York: W.W. Norton and Company.

Miles, M.S., & Crandall, E.K.B. (1986). The search for meaning and its potential for affecting growth in bereaved parents. In R.H. Moos (Ed.). *Coping with Life Crises. An Integrated Approach.* (pp. 235-243). New York: Plenum Press.

Millis, S.R., Rosenthal, M., Novack, T.A., Sherer, M., Nick, T.G., Kreutzer, J.S., High, W.M., & Hicker, J.H. (2001). Long-term neuropsychological outcome after traumatic brain injury. Journal of Head Trauma Rehabilitation, 2001, 16(4), 343-355.

Montada, L., Filipp, S-H., & Lerner, M.J. (1992). *Life crises and experiences of loss in adulthood.* Hillsdale: Lawrence Erlbaum Associates.

Moore, A.D., Stambrook, M., Peters, L.C. (1989). Coping strategies and adjustment after closed traumatic brain injury: a cluster analytical approach. *Brain Injury, 3*(2), 171-175.

Moore, A.D., Stambrook, M. (1992). Coping strategies and locus of control following traumatic brain injury: relationship to long-term outcome. *Brain Injury, 6*(1), 89-94.

Moore, A.D., Stambrook, M., Gill, D.D., & Lubusko, A.A. (1992). Differences in long-term quality of life in married and single traumatic brain injury patients. *Canadian Journal of Rehabilitation, 2,* 89-98.

Moos, R.H. (1982) Coping with acute health crises. In Millon, T., Green, C, & Meagher, R. (Eds.). *Handbook of clinical health psychology.* New York: Plenum Press.

Moos, R.H., & Schaefer, J.A. (1986). Life transitions and crises. In R.H. Moos (Ed.). *Coping with Life Crises. An Integrated Approach.* (pp. 3-28). New York: Plenum Press.

Morrow, G.R., Chiarello, R.J., Derogatis, L.R. (1978). A new scale for assessing patients' psychosocial adjustment to medical illness. *Psychological Medicine, 8,* 605-610.

Morton, M.V., & Wehman, P. (1995). Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. *Brain Injury, 9*(1), 81-92.

Nadell, J. (1991). Towards an existential psychotherapy with the traumatically brain injured patient. *Cognitive Rehabilitation,* November/December, 8-13.

Najenson, T., Mendelson, L., Schechter, I., David, C., Mintz, N., & Grosswasser, Z. (1974). Rehabilitation after severe traumatic brain injury. *Scandinavian Journal of Rehabilitation Medicine, 6*, 5-14.

NAS - The NHS Health Advisory Committee (1997). *Commissioning and providing mental health services for people with Huntingdon's disease, acquired brain injury, and early onset dementia.* London HMSO.

Nelson, L.D., Satz, P., Mitrushina, M., Gorp, W. van, Cicchetti, D., Lewis, R., & Lancker, D. van. (1989). Development and validation of the Neuropsychology Behavior and Affect Profile. *Psychological Assessment: a Journal of Consulting and Clinical Psychology, 1*(4), 266-272.

Nelson, L.D., Mitrushina, M., Satz, P., Sowa, M., & Cohen, S. (1993). Cross-validation of the Neuropsychology Behavior and Affect Profile in stroke patients. *Psychological Assessment: A Journal of Consulting and Clinical Psychology, 5*(3), 374-376.

Newcombe, F. (1982). The psychological consequences of closed traumatic brain injury: Assessment and rehabilitation. *Injury, 14,* 111-136.

NHIF (National Traumatic brain injury Foundation) Task force on special education. (1989*). An educator's manual: What educators need to know about students with traumatic brain injury*. Southborough, MA: NHIF.

Novak, S., Johnson, J., & Greenwood, R. (1996). Barthel revisited: making guidelines work. *Clinical Rehabilitation, 10,* 128-134.

Nunnally, J. C. (1978). Psychometric theory (2nd ed.). New York: McGraw-Hill.

Oatley, K. (1988). Life events, social cognition and depression. In S. Fisher, & J. Reason. *Handbook of Life Stress, Cognition and Health.* (pp. 543-457). Cichester: John Wiley and Sons.

O'Carroll, R.E., Woodrow, J., Maroun, F. (1991). Psychosexual and psychosocial sequelae of closed traumatic brain injury. *Brain Injury, 5*(3), 303-313.

Oddy, M., Humphrey, M., & Uttley, D. (1978). Stresses upon the relatives of brain injured patients. *British Journal of Psychiatry, 133*, 507-513.

Oddy, M., Coughlan, T, Tyerman, A., Jenkins, D. (1985). Social adjustment after closed traumatic brain injury: a further follow-up seven years after injury. *Journal of Neurology, Neurosurgery, and Psychiatry, 48*, 564-568.

Oddy, M., Alcott, D., Francis, E., Jenkins, K., & Fowlie, C. (1999). Methods of evaluation in a cognitive-behavioural rehabilitation programme for brain injury: The experience of Ticehurst House and Unsted Park Hospitals. *Neuropsychological Rehabilitation, 9*(3-4), 373-384.

Ommaya, A.K., & Gennarelli, T.A. (1974). Cerebral concussion and traumatic unconsciousness. *Brain, 97,* 633-654.

Oppenheimer, D.R. (1968). Microscopic lesions in the brain following traumatic brain injury. *Journal of Neurology, Neurosurgery, and Psychiatry, 31,* 299-306.

Osborn, C.L. (1998). *Over my head. A doctor's own story of traumatic brain injury from the inside looking out.* Kansas City: Andrews McMeel Publishing.

Parkes, C.M. (1996). *Bereavement. Studies of Grief in Adult Life*. Third Edition. London: Routledge.

Pavot, W., & Diener, E. (1993). Review of the Satisfaction with Life Scale. *Psychological Assessment, 5*(2), 164-172.

Perrine, K.R. (1993). A new quality of life inventory for epilepsy patients: interim results. *Epilepsia, 34*(Suppl.4), s28-s33.

Perry, W.D. (1986). Surviving traumatic brain injury: a social worker's account. *Health and Social Work*, Summer, 204-208.

Ponsford, J., Sloan, S., and Snow, P. (1995) *Traumatic Brain Injury. Rehabilitation for everyday living*. Hove: Lawrence Erlbaum Associates.

Powell, T. (1995). *Traumatic brain injury. A practical Guide.* Bicester: Winslow Press Limited.

Powell, J. (1999). Assessment of rehabilitation outcomes in community/outreach settings. *Neuropsychological Rehabilitation, 9*(3-4) 457-472.

Prigatano, G.P. (1989, september). Work, love and play after brain injury. *Bulletin of the Menninger Clinic, 53*(5), 414-431.

Prigatano, G.P. (1991). Disturbances of self-awareness of deficit after traumatic brain injury. In: Prigatano, G.P., & Schacter, D.L. *Awareness of deficit after brain injury. Clinical and theoretical issues*. New York: Oxford University Press, pp 111-125.

Prigatano, G.P. (1991). The relationship of frontal lobe damage to diminished awareness: studies in rehabilitation. In: Levin, H.S., Eisenberg, H.M., & Benton, A.L. *Frontal lobe function and dysfunction.* New York: Oxford University Press, pp 381-397.

Prigatano, G.P. (1991). Disordered mind, disordered soul: the emerging role of psychotherapy in rehabilitation after brain injury. *Journal of Head Trauma Rehabilitation, 6*(4), 1-10.

Prigatano, G.P. (1992). Personality disturbances associated with traumatic brain injury. *Journal of Consulting and Clinical Psychology, 60*(3), 360-368.

Prigatano, G.P. (1994). Individuality, lesion location and psychotherapy after brain injury. In A-L Christensen and B. Uzzell (eds.), *Brain injury and neuropsychological Rehabilitation: International Perspective*, (pp. 173-199). Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.

Prigatano, G.P. (1995). 1994 Sheldon Berrol, MD, Senior Lectureship: The problem of lost normality after brain injury. *The Journal of Head Trauma Rehabilitation, 10*(3), 87-95.

Rappaport, M, Hall, K.M., Hopkins, K., Belleza, T., Cope, D.N. (1982). Disability Rating Scale for severe head trauma: coma to community. *Archives of Physiological and Medical Rehabilitation, 63*, 118-123.

Rappaport, M., Herrero-Backe, C., Rappaport, M.L., & Winterfield, K.M. (1989). Traumatic brain injury outcome up to ten years later. *Archieves of Physical Medicine and Rehabilitation, 70,* 885-892.

Reese, H.W., & Smyer, M.A. (1983). The dimensionalization of life events. In E.J. Callahan and K.A. McCluskey (Eds.). *Life-span Developmental Psychology: Nonormative Life Events.* (pp. 131-139). New York: Academic Press.

Revenson, T.A. and Felton, B.J. (1989). Disability and coping as predictors of psychological adjustment to rheumatoid arthritis. *Journal of Consulting and Clinical Psychology, 57*(3), 344-348.

Rosenthal, M., & Bond, M.R. (1990). Behavioral and psychiatric sequelae. In M. Rosenthal, E.R. Griffith, M.R. Bond, & J.D. Miller. *Rehabilitation of the Adult and Child with Traumatic Brain Injury.* Second Edition. (pp. 179-192). Philadelphia: F.A. Davis Company.

Ross, M., & Conway, M. (1986). Remembering one's own past. The construction of personal histories. In R.M. Sorrentino, & E.T. Higgins (Eds.). *Handbook of motivation and cognition. Foundations of social behavior.* (pp. 122-144). Chichester: John Wiley & Sons.

Rowan, K. (1994). Global questions and scores. In: Jenkinson, C. *Measuring health and medical outcomes.* London: University College Press.

Rubin, H.J., & Rubin, I.S. (1995). *Qualitative Interviewing*. Thousand Oakes: Sage.

Ruff, R.M., Marshall, L.F., Crouch, J., Klauber, M.R., Levin, H.S., Barth, J., Kreutzer, J., Blunt, B.A., Foulkes, M.A.,

Eisenberg, H.M., Jane, J.A., Marmarou, A. (1993). Predictors of outcome following severe traumatic brain injury: follow-up data from the traumatic Coma Data Bank. *Brain Injury, 7*(2), 101-111.

Russell, W.R. (1932). Cerebral involvement in traumatic brain injury. *Brain, 55*, 549.

Russell, W.R. (1971). *The traumatic amnesias.* London: Oxford University Press.

Rust, J., & Golombok, S. (1989). *Modern psychometrics*. London: Routledge.

Ruta, D.A., & Garratt, A.M. (1994). Health status to quality of life measurement. In Jenkinson, C. (1994). *Measuring health and medical outcomes.* London: University College Press

Ryant, T.V., Sautter, S.W., Capps, C.F., Meneese, W., Barth, J.E. (1992). Utilizing neuropsychological measures to predict vocational outcome in a head trauma population. *Brain Injury, 6*(2), 175-182.

Ryff, C.D. and Keyes, (1995) Psychological well-being in adult life. *Current Directions in Psychological Science, 4*(4), 99-104.

Sacks, O. (1995). Foreword. In: K. Goldstein. *The Organism.(pp. 7-14).* New York: Zone Books.

Sarafino, E.P. (1990). *Health Psychology. Biopsychosocial interactions*. New York: John Wiley and Sons.

Sbordone, R.J., Liter, J.C., & Pettler-Jennings, P. (1995). Recovery of function following severe traumatic brain injury: a retrospective 10-year follow-up. *Brain Injury, 9*(3), 285-299.

Schacter, D.L., & Prigatano, G.P. (1991). Forms of unawareness. In: Prigatano, G.P., & Schacter, D.L. *Awareness of deficit after brain injury. Clinical and theoretical issues*. New York: Oxford University Press,258-262.

Schalen, W., Hansson, L., Nordström, G., & Nordström, C-H. (1994). Psychosocial outcome 5-8 years after severe traumatic brain lesions and the impact of rehabilitation services. *Brain Injury, 8*(1), 49-64.

Schipper, H. (1990). Quality of Life: principles of the clinical paradigm. *Journal of Psychosical Oncology, 8,* (2/3), 171-185.

Schulz, R., & Decker, S. (1985). Long-term adjustment to physical disability: The role of social support, perceived control, and self-blame. *Journal of Personality and Social Psychology, 48*(5), 1162-1172.

Schwarz, N., & Strack, F. (1991). Evaluating one's life: a judgment model of subjective well-being. In: Strack, F., Argyle, M., & Schwarz, N. *Subjective well-being. An International perspective.* Oxford: Pergamon Press.

Seligman, M.E.P. (1975). *Helplessness: on depression, development, and death.* San Francisco: Freeman.

Selye, H. (1976). *Stress in Health and Disease.* Woburn, MA: Butterworth.

Shadish, W.R., Hickman, D., & Arrick, M.C. (1981). Psychological problems of spinal cord patients: emotional distress as a function of time and lous of control. *Journal of Consulting and Clinical Psychology, 49*, 297.

Sherer, M., Novack, T.A., Sander, A.M., Struchen, M.A., Alderson, A., & Thompson, R.N. (2002). Neuropsychological assessment and employment outcome after traumatic brain injury: a review. *The Clinical Neuropsychologist, 16*(2), 157-178.

Shiel, A., Horn, S.A., Wilson, B.A., McClelland, D.L., Watson, M.J., & Campbell, M. (1999). The Wessex traumatic brain injury matric main scale: a scale to assess and monitor patients recovery after severe traumatic brain injury. *Archives of Physical Medicine and Rehabilitation.*

Shontz, F.C. (1982). Adaptation to chronic illness and disability. In Millon, T., Green, C, & Meagher, R. (Eds.). *Handbook of clinical health psychology*. New York: Plenum Press.

Shuchter, S.R., & Zisook, S. (1993). The course of normal grief. In M.S. Stroebe, W. Stroebe, & R.O. Hansson. *Handbook of Bereavement.* (pp. 23-45). Cambridge: Cambridge University Press.

Silverman, D. (1993). *Interpreting qualitative data*. London: Sage Publications.

Simmons, S. (1994). Quality of life in community mental health care - a review. *International Journal of Nursing Studies, 31*(2), 183-193.

Smith, A. (1961). Duration of impaired consciousness as an index of severity in closed head injuries: A review. *Diseases of the Nervous System, 22*(2), 1-6.

Smith, D.W. (1979). Survivors of serious illness. *American Journal of Nursing, 79,* 441-446.

Smith, H.E. (1992). Traumatic brain injury follow-up: is the Sickness Impact Profile a useful clinical tool? *Clinical Rehabilitation, 6,* 31-39.

Stanton, A.L., Danoff-Burg, S., Cameron, C.L., Snider, P.R., & Kirk, S.B. (1999). Social comparison and adjustment to breast cancer: an experimental examination of upward affiliation and downward evaluation. *Health Psychology, 18*(2), 151-158.

Steadman-Pare, D., Colantonio, A., Ratcliff, G., Chase, S., & Vernich (2001). Factors associated with perceived quality of life many years after traumatic brain injury. *Journal of Head trauma Rehabilitation, 16*(4), 330-342.

Stoker, M.J., Dunbar, G.C., & Beaumont, G. (1992). The SmithKline Beecham 'quality of life' scale: a validation and reliability study in patients with affective disorder. *Quality of Life Research, 1*(6), 385-395.

Stuss, D.T., Gow, C.A., & Hetherington, C.R. (1992). "No longer Gage": Frontal lobe dysfunction and emotional changes. *Journal of Consulting and Clinical Psychology, 60*(3), 349-359.

Sugerman, L. (1986). *Life Span Development. Concepts, Theories and Interventions.* London: Routledge.

Symonds, C.P. (1937). Mental disorder following traumatic brain injury. *Proceedings of the Royal Society of Medicine, 30,* 1081-1092.

Taylor, S.E. (1983). Adjustment to threatening events. A theory of cognitive adaptation. *American Psychologist, 38,* 1161-1173.

Taylor, S.E., & Brown, J.D. (1988). Illusion and well-being: a social psychological perspective on mental health. *Psychological Bulletin, 103*(2), 193-210.

Taylor, S.E., Collins, R.L., Skokan, L.A., & Aspinwall, L.G. (1989). Maintaining positive illusions in the face of negative information: getting the facts without letting the facts get to you. *Journal of Social and Clinical Psychology, 8*(2), 114-129.

Taylor, S.E., Kemeny, M.E., Reed, G.M., & Aspinwall, L.G. (1991). assault on the self: positive illusions and adjustment to threatening events. In: J. Strauss and G.R. Goethals (Eds.). *The self: Interdisciplinary aproaches.* (pp 239-254). New York: Springer-Verlag.

Taylor, S.E., & Brown, J.D. (1994). Positive illusions and well-being revisited: Separating fact from fiction. *Psychological Bulletin, 116*(1), 21-27.

Taylor, S.E. (1995). *Health Psychology.* Third Edition. New York: McGraw-Hill.

Teasdale, G.M., & Jennett, B. (1974). Assessment of coma and impaired consciousness. *Lancet, ii,*81-84.

Teasdale, G.M. (1995). Traumatic brain injury. *Journal of Neurology, Neurosurgery and Psychiatry, 58,* 526-539.

Temkin, N., McLean Jr, A., Dikmen, S., Gale, J., Bergner, M., & Almes, M.J. (1988). Development and evaluation of modifications to the Sickness Impact Profile for traumatic brain injury. *Journal of Clinical Epidemiology, 41*(1), 47-57.

Temkin, N.R., Dikmen, S., Machamer, J., & McLean, A. (1989). General versus disease-specific measures. Further work on the Sickness Impact Profile for traumatic brain injury. *Medical Care, 27*(3 Supplement), S44-S53.

Teuber, H.L. (1960). The premorbid personality and reaction to brain damage. *The American Journal of Orthopsychiatry, 30*(2), 322-329.

Theorell, T. (1992). Critical life changes. A review of research. *Psychotherapy and psychosomatics, 57,* 108-117.

Thoits, P.A. (1983). Dimensions of life events that influence psychological distress: an evaluation and synthesis of the literature. In H.B. Kaplan (Ed.). *Psychosocial Stress. Trends in Theory and Research.* (pp. 33-103). New York: Academic Press.

Thomsen, I.V. (1984). Late outcome of very severe blunt traumatic brain injury: A ten to fifteen year second follow-up. *Journal of Neurology, Neurosurgery, and Psychiatry, 47,* 260-268.

Thomsen, I.V., Waldemar, G., & Thomsen, A.M. (1990). Late psychosocial improvement in a case of severe traumatic brain injury with bilateral fronto-orbital lesions. *Neuropsychology, 4,* 1-11.

Thomsen, I.V. (1992). Late psychosocial outcome in severe traumatic brain injury. *Scandinavian Journal of Rehabilitation, suppl 26,* 142-152.

Truelle, J-L., Brooks, D.N., Potagas, C., & Joseph, P-A. (1994). A European chart for evaluation of patients with traumatic brain injury. In A-L. Christensen, & B.P. Uzzell (Eds.). *Brain Injury and Neuropsychological Rehabilitation: International Perspectives.* (pp. 281-291). Hillsdale: Lawrence Erlbaum Associates.

Tversky, A., & Griffin, D. (1991). Endowment and contrast in judgements of subjective well-being. In: Strack, F., Argyle, M., & Schwarz, N. *Subjective well-being. An International perspective.* Oxford: Pergamon Press.

Tyerman, A., & Humphrey, M. (1984). Changes in self-concept following severe traumatic brain injury. *International Journal of Rehabilitation Research, 7*(1), 11-23.

Tyerman, A. Outcome measurement in a community traumatic brain injury service. *Neuropsychological Rehabilitation, 9*(3-4), 481-492.

Uzzell, B., and Stonnington, H. (1996). *Recovery after traumatic brain injury.* Lawrence Erlbaum Associates.

VanderZee, K.I., Buunk, B.P., & Sanderman, R. (1995). Social comparison as a mediator between health problems and subjective health evaluations. *British Journal of Social Psychology, 34,* 53-65.

VanderZee, K.I., Buunk, B.P., DeRuiter, J.H., Tempelaar, R., VanSonderen, E., & Sanderman, R. (1996). Social comparison and the subjective well-being of cancer patients. *Basic and Applied Social Psychology, 18*(4), 453-468.

Vickrey, B.G. (1993). Procedure for developing a quality-of-life measure for epilepsy surgery patients. *Epilepsia, 34*(suppl. 4) s22-s27.

Viitanen, M., Fugl-Meyer, K.S., Bernspång, B., & Fugl-Meyer, A.R. (1988). Life satisfaction in long-term survivors after stroke. *Scandinavian Journal of Rehabilitation Medicine, 20,* 17-24.

Wade, D.T. (1992). *Measurement in neurological rehabilitation.* Oxford: Oxford University Press.

Webb, C.R., Wrigley, M., Yoels, W., & Fine, P.R. (1995). Explaining quality of life for persons with traumatic brain injury 2 years after injury. *Archives of Physical Medicine and Rehabilitation, 76,* 1113-1119.

Weidner, E.T. (1986). From the patient's point of view. *The Journal of Cognitive Rehabilitation, 4*(2), 4.

White, R.L., & Liddon, S.C. (1972). Ten survivors of cardiac arrest. *Psychiatry in Medicine, 3,* 219-225.

WHO: *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease* (World Health organization, Geneva), 1980.

WHOQOL Group. (1993). Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL). *Quality of Life Research, 2*(2), 153-159.

Whyte, W.F. Interviewing in Field Research. In Burgess, R. (1980). Field Research: A sourcebook and Field Manual. London: Allen and Unwin.

Wilkin, D., Hallam, L., & Doggett, M-A. (1993). *Measures of need and outcome for primary health care.* Oxford: Oxford University Press.

Wilkinson MJB, Barczak P. Psychiatric screening in general practice: comparison of the general health questionnaire and the hospital anxiety depression scale. *J-Roy-Coll-Gen-Prac* 1988; 38: 311-313.

Willer, B., Ottenbacher, K.J., Coad, M.L. (1994). The Community Integration Questionnaire. A comparative examination. *American Journal of Physical Medicine and Rehabilitation, 73*, 103-111.

Willer, B.S., Allen, K.M., Liss, M., & Zicht, M.S. (1991). Problems and coping strategies of individuals with traumatic brain injury and their spouses. *Archives of Physical Medicine and Rehabilitation, 72*, 460-464.

Wills, T.A. (1981). Downward comparison principles in social psychology. *Psychological Bulletin, 90*, 245-271.

Wilson, B. (1991). Long-term prognosis of patients with severe memory disorders. *Neuropsychological Rehabilitation, 1*(2), 117-134.

Wilson, B.A., Shiel, A., Watson, M., Horn, S., & McLellan, L. (1994). Monitoring behavior during coma and posttraumatic amnesia. In: Christensen, A.L., & Uzell, B. (eds). *Brain Injury and neuropsychological rehabilitation*. Hillsdale N.J.: Lawrence Erlbaum Associates.

Wilson, J.T.L., Teasdale, G.M., Hadley, D.M., Wiedmann, K.D., Lang, D. (1993). Post-traumatic amnesia: still a valuable yardstick. *Journal of neurology, neurosurgery and psychiatry, 56*, 198-201.

Witol, A.D., Sander, A.M., Seel, R.T., & Kreutzer, J.S. (1996). Long term neurobehavioral characteristics after brain injury: implications for vocational rehabilitation. *Journal of Vocational Rehabilitation, 7*, 159-167.

Wood, R. Ll. And McMillan, T.M. (2001). *Neurobehavioural disability and social handicap following traumatic brain injury*. Psychology Press: Hove

Wortman, C.B., & Silver, R.C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology, 57*(3), 349-357.

Wortman, C.B., Silver, R.C., & Kessler, R.C. (1993). The meaning of loss and adjustment to bereavement. In M.S. Stroebe, W. Stroebe, & R.O. Hansson. *Handbook of Bereavement*. (pp. 349-366). Cambridge: Cambridge University Press.

Yudofsky, S.C., Silver, S.M., Jackson, W., Endicott, J., & Williams, D. (1986). The overt aggression Scale for the rating of verbal and physical aggression. *American Journal of Psychiatry, 143*, 35-39.

Zahn, B.S., & Littman, S.I. (1989). Depression in survivors of severe traumatic brain injury: issues in assessment and management. *The Psychiatric Forum*, winter, 6-10.

Zec, R.F., Zellers, D., Belman, J., Miller, J., Matthews, J., Ferneau-Belman, D., & Robbs, R. (2001). Long-term consequences of severe closed head injury on episodic memory. Journal of Clinical and Experimental Neuropsychology, 23(5), 671-691.

Zencius, A.H., & Wesolowski, M.D. (1999). Is the social network analysis necessary in the rehabilitation of individuals with traumatic brain injury?. Brain-Injury. 1999 Sep; Vol 13(9), 723-727

Zigmond, A., & Snaith, R. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica, 67*, 361-370.

Zomeren, A.H. van., Burg, W. van den. (1985). Residual complaints of patients two years after severe traumatic brain injury. *Journal of Neurology, Neurosurgery and Psychiatry, 48*, 21-28.

APPENDICES

APPENDIX 5.1.

Ethics approval letter, information sheet and consent form

APPENDIX 5.1.

Ethics approval letter, information sheet and consent form

INFORMATION SHEET FOR PATIENTS

Dear X,

We are writing to invite you to participate in a study to understand better the effects of traumatic brain injury. We need, therefore, to know more about the impact of a traumatic brain injury from your point of view.

After a traumatic brain injury, people sometimes experience difficulties with daily activities. These difficulties can be the direct result of the brain damage (e.g. in the form of physical disabilities or memory problems) or indirect (e.g. the loss of a job). We are concerned about the consequences of a traumatic brain injury in daily life from the point of view of you and your family and friends. We are interested in finding out about progress and recovery, as well as any difficulties you may have met. To that end, we are hoping to work with a number of people who have had head injuries, in order to learn from them what problems have occurred and how they have been dealt with. We would like to meet you in person at home to listen to your comments and those of people close to you. This would take approximately 2-3 hours. With your permission, we would also like to read some of your medical files, in order to understand the difficulties you had to overcome in the past.

The information may be used for presentation only in scientific journals or scientific meetings, in order to share knowledge with other practitioners and hopefully help to improve the quality of services provided for others in the future. No names, addresses or locally named information would be given in order to respect your privacy.

You are free to decide not to take part in this study, and you can leave it at any stage. This would not make any difference to your normal medical care.
We suggest that you keep this letter in case you need to show it to anyone concerned with your medical care.

All the information you provide us with will be treated in the strictest confidence

If you would like to participate, or if you have any questions, do not hesitate to contact me. My telephone number is:

01865 - 552351 or
01865 - 483788

I hope to hear from you soon,

Yours sincerely,

Konrad Jacobs

APPENDIX 5.1.

Ethics approval letter, information sheet and consent form

CONSENT FORM

TTLE OF PROJECT: QUALITY OF LIFE FOLLOWING TRAUMATIC BRAIN INJURY

Naprec No: 1172
Nursing and allied professions research committee

HAVE YOU READ THE INFORMATION SHEET?	YES/NO
HAVE YOU HAD THE CHANCE TO ASK QUESTIONS?	YES/NO
HAVE YOU RECEIVED SATISFACTORY ANSWERS TO YOUR QUESTIONS?	YES/NO

Do you understand that you are free to withdraw from the study/discussions at any time and without having to give a reason for withdrawal? YES/NO

Signed……..

Name……..

Date……..

APPENDIX 5.2.

Qualitative Interview

HINo: |_____|
Date of birth |__|__|__|
Date of examination |__|__|__|
Age at examination |__|__|
Date of accident |__|__|__|
Time post-injury |_____|
Marital Status |__|

Single.....0
Widow.....1
Married.....2
Cohabiting.....3
Divorced/separated.....4

Previous traumatic brain injury with sequelae |__|__|
Psychiatric problems treated by specialist or hospitalisation |__|__|
Pre-existing physical or mental disability |__|__|
Insurance claim settled? |__|
How much? |_____|
Nature of accident |__|

- Road Traffic Accident: Driver ..0; Passenger..1; Pedestrian..2
- Other RTA: motorbike..3; bicycle..4;
- Sport / recreation..5
- Domestic..6
- Assault..7
- Other..8; Specify.....

Severity of accident
length of coma |_____|
PTA |_____|
Epilepsy?
Current medication
Anti convulsants |__|
Major tranquillisers |__|
Benzodiazepines |__|
Anti depressants |__|
Analgesics |__|
Other |__|
Specify_____
Current Clinical Management
Physical Therapy |__|
Occupational therapy |__|
Speech/other cognitive therapy |__|
Psychiatry/psychology |__|
Rehabilitation Physician |__|
Social work/vocational specialist |__|
Other therapy |__|
Specify_____
Educational history |__|

Dyslexia or other educational problems..0
No formal qualifications.....1
'O' levels, GCEs, GCSEs, Vocational.....2
'A' levels, HNC, C&G.....3

APPENDIX 5.2.

Qualitative Interview

Degree or higher.....4
Occupation now |____|
Professional, Executive, Manager.....0
Intermediate; head clerk;
businessman; large scale farmer.....1
Skilled occupations; small farmer;
office worker; foreman; shopkeeper.....2
Semi-skilled occupations, lower
office workers.....3
Unskilled occupations.....4
Student or still at school.....5
Other.....6
No work.....7
Description of work:
Occupation before |____|
Occupational status now |____|
Full time working.....0
Part time working.....1
Unemployed worker.....2
Unemployed (ill).....3
At school.....4
Student: uni / poly.....5
Student: CFE.....6
Other.....7
Occupational status before |____|
Salary range now (Patient only): |____|
0-5000.....0
5000-10.000.....1
10.000-15.000.....2
15.000-20.000.....3
20.000-30.000.....4
30.000-40.000.....5
50.000-.....6
car ownership
Housing
Alcohol intake - now |____| |____|

None.....0
Social (1-2 a week when out socially)...1
Average (<14 units a week).....2
Serious (>14 units a week).....3
Abuse (time off work/treatment for
alcohol dependence.....4
Alcohol intake bafore
What have been the consequences of your accident / traumatic brain injury?
- distinguish between changes in everyday life and changes as a person.
- Are you any different now compared to what you were like before your accident? In what way? Do you feel that anything about you or your abilities has changed?
- Do people you know well notice that anything is different about you since the accident? What might they notice?
- What do you see as your problems, if any, resulting from your injury? What is the main thing you would like to work

APPENDIX 5.2.

Qualitative Interview

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on/would like to get better?
Prompts: physical abilities; memory/confusion; concentration; problem-solving, decision-making, organizing and planning things; ability to do 2 things at once; slowness; reading / writing; controlling behaviour / impulsivity / irritability; communication; getting along with other people; tiredness; headaches; pain; has your personality changed?; any other problems.
- Does your head-injury have any affect on your everyday life? In what way?
Prompts: ability to live independently; managing finances; looking after family/manage home; driving; work/study; leisure/social life.
- Could you describe a typical day? or: what are your hobbies: questions that are more personal than the previous but not too personal yet.

QUALITY OF LIFE

(1) open-ended

® How are things for you now? How do you feel about your life nowadays?

® Could you tell me about the aspects of your life that are not satisfactory? What is it that you do not like about your life at the moment?

® Could you tell me about the aspects of your life that are satisfactory? What is it that you do like about your life at the moment?

® I am interested to hear about your recovery and the way you have dealt with the problems you have met on the way.
1- Could you tell me briefly what has happened to you from the moment you opened your eyes in the hospital to now?
2- "It must have been very difficult for you after your accident: one moment you are a healthy young man, the next moment you have all these limitations. Was it difficult for you?"
Probe how he views how he has developed since the accident. Ask for different stages.
3- what would you say has been your worst moment during your recovery / what was your lowest point?
4- have you ever thought of ending it all? (only if patient is stable); no thoughts; is thinking about it now; has thought about it, not attempted; has attempted
5- do you feel that you have made a good recovery / do you feel that you are exactly the same or close to the way you were before the accident?
6- do you feel that you are a normal person?

Do you feel that anything good has come out of it all / out of the fact that you had this accident X years ago?
did you learn from the experience?
do you value your life more now than you did before?
do you feel that you have grown as a person as a result of your experience?

(2) semi-structured

Patients are asked whether this aspect is important in their life and how satisfied they are with this aspect of their life?

® How do you feel about your ability to take care of yourself (hair, face, shaving, dressing, hygiene, grooming)?
® How do you feel about your physical abilities?
® How do you feel about your mental abilities?
® How do you feel about your leisure opportunities / activities (hobbies, sport, interests)?
® How do you feel about work at present? has it affected your job prospects / your career path?
® How do you feel about your financial situation?
® How do you feel about your level of independence? do you feel 'free' / that you can decide over your own life?
® How do you feel about your relationship with your partner?

APPENDIX 5.2.

Qualitative Interview

® How do you feel about your family life?
® How do you feel about your contacts with friends and acquaintances?
® How do you feel about your sexual life?
® How do you feel about the way you spend your days? are you bored a lot?
® How do you feel about your aims and purposes in life? do you feel that there is a meaning to life/do you feel that there is a purpose?
® How do you feel about your religious/spiritual life?
® How do you feel about your life as a whole?

Acceptance

® Would your life have been different if you did not suffer from the consequences of your traumatic brain injury?
® In what respect?
® How do you feel about this?
® Do you often think about what might have been if you did not suffer from the consequences of a traumatic brain injury?
® Would you say you have (had) a hard time adjusting to the limitations of your traumatic brain injury?
distinguish between changes in everyday life and changes as a person. one may be more difficult to accept than the other.
® What would you say has helped you (most) adjust to your limitations?
® All in all, would you say you have accepted the fact that you are no longer the person you were before the accident?

'Break' with past

Would you say you look more towards the past than the future? Has there been a moment in time at which you felt that you were no longer thinking about your accident and it's consequences as much as you did before, but instead started thinking about what lies ahead of you?

For carers only:

Awareness / insight / denial / avoidance

® You have described to me how X has changed since the accident: a, b, c.
Would you say that X always realises fully how and to what extent he has changed?
® Do you think he understands how he has changed?
® What is X's reaction when he is confronted with his limitations / changes?
Perplexing / anger; irritation;

Expectations and aims for the future

What do you hope to achieve in the future? Do you have any goals? What are they?

work
relationships
family
independent living
loneliness
leisure / hobbies

What do you think you will be doing in the future? Where do you think you will be?
Do you think your traumatic brain injury will still be having an effect on you in the future?
if yes: how; if no: are you sure?

APPENDIX 5.2.

Qualitative Interview

® In general, how do you feel about the future?
® In general, do you look forward to the future?
® Optimistic / pessimistic?
® What would you most like to happen/change in the future?
® How do you expect to be in 5 years from now?
® You mentioned that you are not satisfied with X, Y, Z. How do you think your X, Y, Z will be / develop in the future?
® What is the best you hope for in the future?
® What would you be prepared to settle for / be content with?

Comparison

1- do you often think about the things that you could do before the accident but can't do anymore?
2- do you often think about the things you could not do after the accident but can do now, because you have recovered?
3- do you often compare yourself to other people who have had a traumatic brain injury and do you consider yourself lucky?
4- do you often compare yourself to other people who have not had a traumatic brain injury?

APPENDIX 5.3.

Categories used in the qualitative study

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1. How happy is the HI person (HI person's perspective)?

- ❑ Not Happy; (the person generally makes a very unhappy impression; cannot come up with many things to be happy about; can come up with important aspects of his life which he is unhappy about; directly replies `no' the question of whether he is happy)
- ❑ Moderately happy; (the person makes neither a happy, nor an unhappy impression; some days are good, some days are bad; can come up with things he is not happy about and things that he is happy about)
- ❑ Happy; (the person generally makes a happy impression; things generally seem to go well for him; cannot come up with many things to be unhappy about; can come up with important aspects to his life to be happy about; directly replies `yes' to the question of whether he is happy)

(Base judgement on:
- Direct question to the patient: "are you happy with your life?"
- General impression

2. How happy is the HI person (carer's perspective)?

- ❑ Not Happy; (according to the carer, the brain injured person is generally unhappy; the carer cannot come up with many things the HI person is happy about; can come up with important aspects of the HI person's life which he is unhappy about; the carer directly replies `no' the question of whether the HI person is happy)
- ❑ Moderately happy; (according to the carer, the HI person makes neither a happy, nor an unhappy impression; some days are good, some days are bad; can come up with things the HI person is not happy about and things that the HI person is happy about)
- ❑ Happy; (according to the carer, the HI person generally makes a happy impression; things generally seem to go well for the HI person; the carer cannot come up with many things the HI person is unhappy about; can come up with important aspects of the HI person's life to be happy about; directly replies `yes' to the question of whether he is happy)

(Base judgement on:
- Direct question to the carer: "are you happy with your life?"
- General impression the carer gives of the subject

3. What is he unhappy about at the moment (brain injured person's perspective)?

- ❑ Cognitive (memory; concentration; language; perception; motor speed; etc)
- ❑ Medical (headache; pain; seizures; mobility; neurological deficits)
- ❑ Living (Location or type of residence; independence)
- ❑ Job / school (finding work; holding a job, salary, type of work;)
- ❑ Behaviour (aggressiveness; inappropriateness; sexual acting out)
- ❑ Emotional (depression; guilt; anger; lability; frustration)
- ❑ Chemical (alcohol; drugs)
- ❑ Loneliness/lack of friends
- ❑ Loss of independence (mobility; independent living)
- ❑ Difficulty finding / maintaining a relationship
- ❑ Lack of sexual contact
- ❑ Tiredness
- ❑ What other people think of him
- ❑ Other.....

(Base judgement on:

APPENDIX 5.3.

Categories used in the qualitative study

- Direct question to the patient: "what are you unhappy about at the moment?"

4. What is he happy about at the moment (HI person's perspective)?

- ❑ Being with friends
- ❑ Family
- ❑ To be alive
- ❑ Freedom
- ❑ Financial security
- ❑ Leisure / sport / hobbies
- ❑ Relation with partner
- ❑ Other.....

(Base judgement on:

- Direct question to the patient: "what are you happy about at the moment?"

5. Reasons for the brain injured person's unhappiness (carer's perspective)

For categories: see number 3

6. Reasons for brain injured person's happiness (carer's perspective)

For categories: see number 4

7. Self-awareness of deficit (Fleming et al., 1993)

1. Cognitive / psychological problems (where relevant) reported by the patient / client in response to general questioning, or readily acknowledged in response to specific questioning
2. Some cognitive / psychological problems reported, but others denied or minimised. Patient / client may have a tendency to focus on relatively minor physical changes (e.g. scars) and acknowledge cognitive / psychological problems only on specific questioning about deficits.
3. Physical deficits only acknowledged; denies, minimises or is unsure of cognitive / psychological changes. Patient / client may recognise problems that occurred at an earlier stage but denies existence of persisting deficits, or may state that other people think there are deficits, but he/she does not think so.
4. No acknowledgement of deficits (other than obvious physical deficits) can be obtained, or patient / client will only acknowledge problems that have been imposed on him, e.g. not allowed to drive, not allowed to drink alcohol.

(Base judgement on:

- Comparison of the deficits the subject mentions and the deficits the carer mentions
- Direct question to the carer: "does the subject have full insight/awareness?"
- General impression

8. Self-awareness of functional implications of deficits, i.e. the implications of his deficits in his daily life

1. Patient / client accurately describes current functional status (in independent living, work/study, leisure, home management, driving), and specifies how his traumatic brain injury problems limit function where relevant, and/or any compensatory measures to overcome problems.
2. Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient / client may not be sure of other likely functional problems, e.g. is unable to say because he has not tried an activity yet.
3. Patient / client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient / client
4. Little acknowledgement of functional consequences can be obtained; the patient / client will not acknowledge problems: except that he is not allowed to perform certain tasks. He may actively ignore medical advice and may not engage in risk-taking behaviours, e.g. drinking, driving.

APPENDIX 5.3.

Categories used in the qualitative study

(Base judgement on:
- Comparison of the problems the subject mentions and the deficits the carer mentions
- Direct question to the carer: "does the subject have full insight/awareness?"
- General impression

Comment on 5 and 6:
Before it can be said that the patient has a lack of awareness, it has to be clear that there are actually consequences of the traumatic brain injury. This can be checked by going through the interview with the significant other or a medical report on the patient.

9. Acceptance (Patient's perspective)

1. Full acceptance: The brain injured person says he has accepted his limitations and exhibits the following (Ben-Yishay, 1988):

he generally shows calm resignation to the reality that the injury has changed one's life in many respects and that it has imposed certain restrictions on what one may achieve in the future
the conviction that life, as is, plus the future (realistic) options that remain available, can be tolerated with a "calm dignity", without undue agitation, and without feeling that one has been totally "vanquished" by life and rendered into a "has been".
the ability to derive from one's present life some satisfactions, (which make one's life "worthwhile", and help healing one's shattered sense of "self"; and this, in spite of the fact that one's present and probably future ability to achieve has become diminished compared with the pre injury status)

2. Some acceptance: The patient has clearly not adjusted himself fully to the consequences yet, but has made some progress. He may have accepted some changes, but not others.
3. No acceptance: The brain injured person says he has not accepted his limitations and generally exhibits the opposite of the conditions mentioned under full acceptance
4. Don't know

(Base judgement on:
- Direct question to the patient: "do you feel that you have accepted your limitations?"
- Direct questions to the patient: "do you often think about what might have been if you had not had a traumatic brain injury?" and "do you feel that you are still struggling every day?"
- General impression

10. Subject's Acceptance of limitations (carer's perspective)
See question number nine for categories

(Base judgement on:
- Direct question to the carer: "do you feel that he has accepted his limitations?"
- Direct questions to the carer: "does he often think about what might have been if he had not had a traumatic brain injury?" and "do you feel that he is still struggling every day?"
- General impression

11. Subject's acceptance of limitations
See question number nine for categories

(Base judgement on:
- Observers' s own judgement on whether the patient is still struggling with the consequences of the hi of whether he has managed to let go.

12. Would life have been different if he had not had the accident?

APPENDIX 5.3.

Categories used in the qualitative study

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1. Yes
2. No
3. maybe/don't know

(Base judgement on:
- Direct question to the patient: would your life have been different if you had not had the accident?

13. Does he often think about what might have been if you had not had the accident? (patient's perspective)

1. Yes
2. No
3. maybe/don't know

(Base judgement on:
- Direct question to the patient: do you often think about what might have been?

14. Does he often think about what might have been if you had not had the accident? (carer's perspective)

1. Yes
2. No
3. maybe/don't know

(Base judgement on:
- Direct question to the carer: does he often think about what might have been?

15. Has there been a `break' with the past? Has there been a moment in time at which the patient felt that he was no longer looking thinking about the accident and its consequences as much as he did before, but instead started thinking more about what lies ahead of him?

PATIENT'S PERSPECTIVE

1. Is definitely still preoccupied with the past
2. Lives only in the here and now; lives from day to day; looks neither to the past nor to the future
3. Has plans for the future; is forward-looking;
4. maybe/don't know

(Base judgement on:
- Direct question to the patient: "has there been a break with the past?"

16. Has there been a `break' with the past? Has there been a moment in time at which the patient felt that he was no longer looking thinking about the accident and its consequences as much as he did before, but instead started thinking more about what lies ahead of him?

CARER'S PERSPECTIVE

1. Is definitely still preoccupied with the past
2. Lives only in the here and now; lives from day to day; looks neither to the past nor to the future
3. Has plans for the future; is forward-looking;
4. maybe/don't know

(Base judgment on:
- Direct question to the carer: "has there been a break with the past for the patient?"

17. Depression (according to the patient)

APPENDIX 5.3.

Categories used in the qualitative study

1. Has been depressed at some stage during the recovery
2. Has not been depressed at some stage during the recovery
3. maybe/don't know

(- Base judgement on:
Direct question to the patient: "have you been depressed at any stage during the recovery?"

18. Depression (according to the carer)
1. Has been depressed at some stage during the recovery
2. Has not been depressed at some stage during the recovery
3. maybe/don't know

(- Base judgement on:
Direct question to the carer: "has he been depressed at any stage during the recovery?"

19. Suicide (according to the patient)
1. has never considered it
2. has thought about it, but never seriously
3. has seriously considered suicide but has never attempted it
4. has attempted suicide
5. maybe/don't know

(- Base judgement on:
Direct question to the patient: "have you ever thought of ending it all?"

20. Suicide (according to the carer)
1. has never considered it
2. has thought about it, but never seriously
3. has seriously considered suicide but has never attempted it
4. has attempted suicide
5. maybe/don't know

(- Base judgement on:
Direct question to the carer: "has he ever thought of ending it all?"

21. Suicide (patient and carer)
1. has never considered it
2. has thought about it, but never seriously
3. has seriously considered suicide but has never attempted it
4. has attempted suicide
5. maybe/don't know

(- Base judgement on:
4, 3, and 2 are scored if either the brain injured person or his significant other indicate that this has happened; I have put this one in because sometimes only one mentions a suicide attempt.

22. Comparison pre injury - now (patient's perspective)
1. never thinks about the things he could do before the accident but not any more
2. sometimes thinks about the things he could do before the accident but not an more
3. often thinks about the things he could do before the accident but not any more
4. maybe/don't know

APPENDIX 5.3.

Categories used in the qualitative study

(Base judgement on:
- Direct question to the patient: "do you often think about the things you could do before the accident but can't do now?"

23. Comparison pre injury - now (carer's perspective)
1. never thinks about the things he could do before the accident but not any more
2. sometimes thinks about the things he could do before the accident but not an more
3. often thinks about the things he could do before the accident but not any more
4. maybe/don't know

(Base judgement on:
- Direct question to the carer: "does he often think about the things he could do before the accident but can't do now?"

24. Comparison post injury - now (patient's perspective)
1. never thinks about the things he could not do after the accident but can do now
2. sometimes thinks about the things he could not do after the accident but can do now
3. often thinks about the things he could not do after the accident but can do now
4. maybe/don't know

(Base judgement on:
- Direct question to the patient: "do you often think about the things you could not do after the accident, but can do now because you have recovered?"

25. Comparison post injury - now (carer's perspective)
1. never thinks about the things he could not do after the accident but can do now
2. sometimes thinks about the things he could not do after the accident but can do now
3. often thinks about the things he could not do after the accident but can do now
4. maybe/don't know

(Base judgement on:
- Direct question to the patient: "does he often think about the things he could not do after the accident, but can do now because he has recovered?"

26. Does the patient think that he is better off than other people who have had a traumatic brain injury?
1. Yes
2. No
3. maybe/don't know

(Base judgement on:
- Direct question to the patient: "do you ever compare yourself to other people who have had a traumatic brain injury and do you feel that you are lucky?"

27. Does the patient ever compare himself to normal, healthy people
1. Yes
2. No
3. maybe/don't know

(Base judgement on:
- Direct question to the patient: "do you ever compare yourself to people who have not had a HI?"

APPENDIX 5.3.

Categories used in the qualitative study

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28. Does the brain injured person report positive effects of the traumatic brain injury?

1. Yes
2. No
3. maybe/don't know

(Base judgement on:
- Direct question to the patient: "do you feel that anything positive has come out of the fact that you had a traumatic brain injury?"

29. Does the carer report positive effects of the traumatic brain injury for the patient?

1. Yes
2. No
3. maybe/don't know

(Base judgement on:
- Direct question to the carer: "do you feel that anything positive for him has come out of the fact that the patient had a traumatic brain injury."

30. Domains of positive changes (HI person) (Lehman et al., 1993)

1. Self-perception: Feelings of strength or increased sense of self as a result of loss;
("My HI has helped me learn about myself"; "Because of my HI, I know that I have a lot of will power/determination"; "I feel proud that I have been through all this and that I am still here"
2. Social relation; Increased concern for others; increased emphasis on the family
"My HI has shown me the value of close friends"; "My HI has shown me the value of a close family")
3. Life orientation; Greater appreciation for life; increased religiosity/faith; focus on enjoying the present; increased acceptance of reality; ("My HI has helped me value my life more now"; "I am better off now after my HI, because I was destroying myself before"
4. maybe/don't know

(Base judgement on:
- Direct question to the patient: "what positive things have come out of the fact that you had a traumatic brain injury?"

31. Does the patient have a realistic view of the future? (Fleming et al.)

1. Patient / client sets reasonably realistic goals, and (where relevant) identifies that the traumatic brain injury will probably continue to have an impact on some areas of functioning, i.e. goals for the future have been modified in some way since the injury.
2. Patient / client sets goals which are somewhat unrealistic, or is unable to specify a goal, but recognises that he may still have problems in some areas of function in the future, i.e. sees that goals for the future may need some modification, even if he has not yet doen so.
3. Patient / client sets unrealistic goals, or is unable to specify a goal, and does not know how he will be functioning in the future
4. maybe/don't know

(Base judgement on:
- Direct question to the carer: "do you feel that he has a realistic view of the future?"
- General impression during the interview (if he thinks he can become a football player, while sitting in a wheelchair, then that counts as an unrealistic view of the future).

32. Does the patient have a short fuse/temper?

APPENDIX 5.3.

Categories used in the qualitative study

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1. Yes, significant/severe problems with temper
2. Yes, mild/moderate problems with temper
3. No, no problems with temper

(Base judgement on:
- Question to the carer: does he have a short fuse/problems with his temper?

33. Is the patient impulsive?

1. Yes, significant/severe impulsivity
2. Yes, mild.moderate impulsivity
3. No, not impulsive

(Base judgement on:
- Question to the carer: is the patient impulsive/does he do or say things without thinking first?

APPENDIX 5.4.

Coding for the qualitative study

Subject No.....

1. Happiness Patient's perspective Only 1 option possible	1	2	3			
2. Happiness Carer's perspective Only 1 option possible	1	2	3			
3. Reasons for unhappiness Patient's perspective More than 1 option possible	1	2	3	4	5	6
	7	8	9	10	11	
	12	13	14 Other.....			
4. Reasons for happiness Patient's perspective More than 1 option possible	1	2	3	4		
	5	6	7	8		
	Other.....					
5. Reasons for unhappiness Carer's perspective More than 1 option possible	1	2	3	4		
	5	6				
	7	8	9			
	10	11	12			
	13	14 Other.....				
6. Reasons for happiness Carer's perspective More than 1 option possible	1	2	3	4		
	5	6	7	8		
	Other.....					
7. Self-awareness of deficit Only 1 option possible	1	2	3	4		
8. Self-awareness of functional implications Only 1 option possible	1	2	3	4		
9. Acceptance of limitations Patient's perspective Only 1 option possible	1	2	3	4		
10. Subject's Acceptance of limitations	1	2	3	4		

APPENDIX 5.4.

Coding for the qualitative study

Carer's perspective Only 1 option possible					
11. Subject's Acceptance of limitations observer's perspective Only 1 option possible	1	2	3	4	
12. Would life have been different without traumatic brain injury? Patient's perspective Only 1 option possible		1	2	3	4
13. Does he often think about what might have been? Patient's perspective Only 1 option possible	1	2	3	4	
14. Does he often think about what might have been? Carer's perspective Only 1 option possible	1	2	3	4	
15. Has there been a break with the past Patient's perspective Only 1 option possible		1	2	3	4
16. Has there been a break with the past Carer's perspective Only 1 option possible		1	2	3	4
17. Depression during the recovery Patient's perspective Only 1 option possible		1	2	3	
18. Depression during the recovery Carer's perspective Only 1 option possible	1	2	3		
19. Suicide Patient's perspective Only 1 option possible	1	2	3	4	5
20. Suicide Carer's perspective Only 1 option possible	1	2	3	4	5
21. Suicide (patient and carer) Only 1 option possible	1	2	3	4	5

APPENDIX 5.4.

Coding for the qualitative study

22. Comparison pre-injury-now Patient's perspective Only 1 option possible	1	2	3	4
23. Comparison pre-injury-now Carer's perspective Only 1 option possible	1	2	3	4
24. Comparison post-injury-now Patient's perspective Only 1 option possible	1	2	3	4
25. Comparison post-injury-now Carer's perspective Only 1 option possible	1	2	3	4
26. Better off than other people with a traumatic brain injury? Only 1 option possible		1	2	3
27. Comparison with normal, healthy people Only 1 option possible	1	2	3	
28. Positive effects Patient's perspective Only 1 option possible	1	2	3	
29. Positive effects Carer's perspective Only 1 option possible	1	2	3	
30. Domains of positive change More than 1 option possible	1	2	3	4
31. Realistic views for the future Only 1 option possible	1	2	3	4
32. Short fuse/temper Only 1 option possible	1	2	3	
33. Impulsivity Only 1 option possible	1	2	3	

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APPENDIX 6.1.

Domains used in quality of life measures in different fields

Authors / key reference	Name of the scale	Scale intended for	Domains
WHOQOL group (1993)	WHOQOL	A generic QOL measure	Physical health; psychological health; level of independence; social relationships; environment;
Baker and Intagliate (1982)		Review of QOL domains most commonly viewed as relevant to QOL assessments	Work; leisure; relation with family members; relations with friends; financial situation; health; social and physical environment; self- fulfilment;
Beaufait et al. (1992)	COOP Charts	A generic QOL Scale	Physical; emotional; social; role; global health; health change; pain; overall QOL; social support;
Lehman et al. (1982)	QOL Interview	To assess QOL of severely mentally ill people	The psychological functioning subscale: general perceived health status; general life satisfaction; satisfaction with living situation; family relations; social relations; leisure; work; religious activities; finances; safety, and health;
Endicott et al. (1993)	QOL Enjoyment and Satisfaction Questionnaire	Participants with a wide variety of mental and medical disorders	Physical health; subjective feelings; work; household duties; school/course work; leisure; social relationships; general activities;
Bigelow et al. (1990)	The QOL Questionnaire	People with mental health problems	Psychological distress; ; well-being; ability to cope with stress; basic need satisfaction; independence; interpersonal interaction; spouse role; social support; work at home; work in a job; employability; meaningful use of time; negative consequences of alcohol; negative consequences of drug use;
Stoker et al. (1992)	The SmithKline Beecham QOL Scale	Patients with major depression or generalised anxiety disorder	Physical well-being; psychic well-being; mood; locus of control; social relationships; work/employment; activities/interests; finance;
Heinrichs et al. (1984)	QOL Scale	Patients with schizophrenia	Sense of purpose; motivation; curiosity; anhedonia; aimless activity; empathy; emotional interaction; work satisfaction; interpersonal relations; occupational role; work functioning; work level; possession of commonplace objects; commonplace activities;
Pinkney et al. (1991)	Clients' QOL Instrument	Mainly patients with schizophrenia	Leisure and recreation; employment; education; finances; living arrangements; social activity; involvement with family, friends and community; ability to cope;
Cramer (1993)		Suggested health-related QOL domains in epilepsy	Physical (daily function; general health; seizures; adverse effects); Psychological (perception of general well-being; self-esteem; depression; anxiety; concentration; memory; cognition); Social (family; friend, co-worker relationships); Economic (occupational status; income)
Vickrey (1993)	The Epilepsy Surgery Inventory	Developed to evaluate outcome after epilepsy surgery	Emotional well-being; role limitations due to emotional problems; energy/fatigue; social function; role limitations due to physical problems; health perceptions; cognitive function; role limitations due to memory problems; overall QOL; change in health;
Peto et al. (1995)		Developed for use with Parkinson patients	8 domains are included besides the SF-36: mobility; activities of daily living; emotional well-being; stigma; social support; cognitions; communications and bodily discomfort

APPENDIX 6.2.

Results of a principal components factor analysis of 14 domains of life satisfaction in the student sample

Descriptive Statistics

	Mean	Std. Deviation	Analysis N
S1CARE	5.2478	.72618	113
S1INDEP	4.9381	.71067	113
S1PHYS	4.8319	.84413	113
S1MENTAL	4.6637	.81952	113
S1LEISUR	4.4513	.97276	113
S1WORK	4.4867	.99207	113
S1FINANC	3.8230	1.32443	113
S1FAMILY	4.6106	1.26374	113
S1FRIEND	4.9558	.87003	113
S1SEX	4.2566	1.26617	113
S1DAYS	4.3717	.74636	113
S1AIMS	4.6106	.99493	113
S1YOURSE	4.4602	1.11832	113
S1RELIGI	4.6549	.93322	113

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.967	28.333	28.333	3.967	28.333	28.333
2	1.393	9.949	38.282	1.393	9.949	38.282
3	1.221	8.722	47.004	1.221	8.722	47.004
4	1.118	7.985	54.988	1.118	7.985	54.988
5	1.078	7.697	62.685	1.078	7.697	62.685
6	.918	6.554	69.239			
7	.780	5.571	74.810			
8	.702	5.017	79.826			
9	.632	4.511	84.337			
10	.535	3.823	88.160			
11	.504	3.600	91.760			
12	.476	3.397	95.158			
13	.356	2.544	97.701			
14	.322	2.299	100.000			

Extraction Method: Principal Component Analysis.

Component Matrix [a]

	Component				
	1	2	3	4	5
S1CARE	.180	.419	-.655	.119	2.627E-02
S1INDEP	.433	.355	-.219	-.266	.233
S1PHYS	.500	.166	-.154	.400	.225
S1MENTAL	.717	-.123	-.242	.131	8.988E-02
S1LEISUR	.578	-.199	.270	.332	-.101
S1WORK	.637	6.782E-03	-.166	-.309	-.334
S1FINANC	.424	.503	.462	.143	-.199
S1FAMILY	.409	.546	.163	.324	.161
S1FRIEND	.342	-.362	.158	.464	-.145
S1SEX	.269	.209	.499	-.422	.434
S1DAYS	.728	-.181	.143	-.232	-8.75E-04
S1AIMS	.754	-.117	-1.71E-02	-.219	-.274
S1YOURSE	.728	-.188	-.152	-.161	-6.52E-02
S1RELIGI	.280	-.449	-6.60E-02	6.264E-02	.698

Extraction Method: Principal Component Analysis.

a. 5 components extracted.

APPENDIX 6.3.

Results of a principal components factor analysis of 14 domains of 'importance' in the student sample

Descriptive Statistics

	Mean	Std. Deviation	Analysis N
L1CARE	5.48	.830	120
L1INDEP	5.41	.716	120
L1PHYS	5.58	.589	120
L1MENTAL	5.67	.678	120
L1LEISUR	5.0250	.81439	120
L1WORK	5.2083	.78746	120
L1FINANC	4.9583	.86380	120
L1FAMILY	5.3250	.94524	120
L1FRIEND	5.3000	.79494	120
L1SEX	4.3583	1.07528	120
L1DAYS	4.6500	.92264	120
L1AIMS	5.2083	.82905	120
L1YOURSE	5.3167	.70987	120
L1RELIGI	2.7833	1.46777	120

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	2.899	20.704	20.704	2.899	20.704	20.704
2	1.550	11.069	31.774	1.550	11.069	31.774
3	1.302	9.298	41.072	1.302	9.298	41.072
4	1.208	8.625	49.697	1.208	8.625	49.697
5	1.084	7.744	57.441	1.084	7.744	57.441
6	1.005	7.179	64.620	1.005	7.179	64.620
7	.855	6.109	70.729			
8	.836	5.974	76.704			
9	.751	5.363	82.066			
10	.687	4.909	86.976			
11	.573	4.091	91.066			
12	.499	3.564	94.630			
13	.397	2.833	97.463			
14	.355	2.537	100.000			

Extraction Method: Principal Component Analysis.

Component Matrix [a]

	Component					
	1	2	3	4	5	6
L1CARE	.420	.183	-.380	.401	9.410E-02	.157
L1INDEP	.613	-.188	4.663E-03	.382	-.255	-.155
L1PHYS	.206	-.393	.442	.120	.308	.476
L1MENTAL	.479	-.523	-6.13E-02	.279	-.141	.130
L1LEISUR	.350	.287	.479	.264	.171	-.161
L1WORK	.640	-.176	-.249	1.893E-02	.300	-.153
L1FINANC	.272	.391	-2.99E-03	.408	.408	-.211
L1FAMILY	.210	.353	-.432	-.331	.435	.339
L1FRIEND	.131	.718	.268	4.287E-02	-.272	-8.21E-02
L1SEX	.337	.239	.413	-.109	-5.69E-02	.560
L1DAYS	.573	-1.08E-03	.232	-.268	-.242	-7.96E-02
L1AIMS	.693	-.114	-5.71E-02	-.449	-.115	-.157
L1YOURSE	.582	2.312E-03	.118	-.412	.210	-.232
L1RELIGI	.383	.276	-.410	7.463E-02	-.476	.315

Extraction Method: Principal Component Analysis.

a. 6 components extracted.

APPENDIX 7.1.

Pair-wise comparisons between patient-perceived domains of satisfaction (Wilcoxon Signed Ranks Test)

	M	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Ability to take care of oneself	4.96	--	ns	ns	ns	ns	***	***	***	***	***	***	***	***	***	***	***	***
2. Religious life	4.86		--	ns	ns	ns	ns	ns	ns	***	***	***	***	***	ns	ns	***	***
3. Relationship with partner	4.78			--	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	n/a
4. Family life	4.53				--	ns	ns	ns	ns	ns	***	***	***	ns	ns	ns	***	***
5. Independence	4.15					--	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	***
6. Physical abilities	4.06						--	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
7. Friendships	3.96							--	ns	ns	ns	ns	ns	ns	ns	ns	ns	***
8. Life in general	3.93								--	ns	ns	ns	ns	ns	ns	ns	ns	***
9. Mental abilities	3.87									--	ns	ns	ns	ns	ns	ns	***	
10. Aims	3.87										--	ns	ns	ns	ns	ns	***	
11. Spending days	3.87											--	ns	ns	ns	ns	ns	***
12. Yourself	3.78												--	ns	ns	ns	ns	***
13. Leisure	3.77													--	ns	ns	ns	***
14. Financial situation	3.73														--	ns	ns	***
15. Work	3.66															--	ns	***
16. Sexual Life	3.13																--	ns
17. No Partner	2.14																	--

*** Represents $p < .001$; ns Not Significant

(b) Comparisons are pairwise; The averages compared may therefore not be the averages shown in the table

APPENDIX 7.2.

Mean ranks and numbers in both the brain injured and the control group on the Satisfaction with Life Domains Scale

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Ranks

	Group	N	Mean Rank	Sum of Ranks
S1CARE	Normal controls	49	51.31	2514.00
	Head injury	48	46.65	2239.00
	Total	97		
S1INDEP	Normal controls	49	54.55	2673.00
	Head injury	46	41.02	1887.00
	Total	95		
S1PHYS	Normal controls	48	53.08	2548.00
	Head injury	48	43.92	2108.00
	Total	96		
S1MENTAL	Normal controls	48	59.18	2840.50
	Head injury	48	37.82	1815.50
	Total	96		
S1LEISUR	Normal controls	49	55.50	2719.50
	Head injury	47	41.20	1936.50
	Total	96		
S1WORK	Normal controls	48	46.34	2224.50
	Head injury	47	49.69	2335.50
	Total	95		
S1FINANC	Normal controls	48	41.89	2010.50
	Head injury	48	55.11	2645.50
	Total	96		
S1PARTY	Normal controls	29	25.14	729.00
	Head injury	18	22.17	399.00
	Total	47		
S1PARTN	Normal controls	16	31.81	509.00
	Head injury	29	18.14	526.00
	Total	45		
S1FAMILY	Normal controls	49	45.36	2222.50
	Head injury	45	49.83	2242.50
	Total	94		
S1FRIEND	Normal controls	48	53.57	2571.50
	Head injury	48	43.43	2084.50
	Total	96		
S1SEX	Normal controls	47	56.65	2662.50
	Head injury	45	35.90	1615.50
	Total	92		
S1DAYS	Normal controls	48	47.96	2302.00
	Head injury	45	45.98	2069.00
	Total	93		
S1AIMS	Normal controls	47	49.57	2330.00
	Head injury	47	45.43	2135.00
	Total	94		
S1YRSELF	Normal controls	46	51.89	2387.00
	Head injury	46	41.11	1891.00
	Total	92		
S1RELIGI	Normal controls	41	36.76	1507.00
	Head injury	37	42.54	1574.00
	Total	78		
S1LIFE	Normal controls	48	48.92	2348.00
	Head injury	45	44.96	2023.00
	Total	93		

APPENDIX 7.3.

Mean ranks and numbers in both the brain injured and the control group on the Life Priority Scale

Ranks

	Group	N	Mean Rank	Sum of Ranks
L1CARE	Normal controls	48	44.54	2138.00
	Head injury	45	49.62	2233.00
	Total	93		
L1INDEP	Normal controls	49	46.40	2273.50
	Head injury	45	48.70	2191.50
	Total	94		
L1PHYS	Normal controls	49	43.30	2121.50
	Head injury	45	52.08	2343.50
	Total	94		
L1MENTAL	Normal controls	49	47.94	2349.00
	Head injury	44	45.95	2022.00
	Total	93		
L1LEISUR	Normal controls	49	47.92	2348.00
	Head injury	45	47.04	2117.00
	Total	94		
L1WORK	Normal controls	48	47.79	2294.00
	Head injury	44	45.09	1984.00
	Total	92		
L1FINANC	Normal controls	47	42.98	2020.00
	Head injury	43	48.26	2075.00
	Total	90		
L1PARTY	Normal controls	34	24.88	846.00
	Head injury	14	23.57	330.00
	Total	48		
L1PARTN	Normal controls	16	20.09	321.50
	Head injury	29	24.60	713.50
	Total	45		
L1FAMILY	Normal controls	48	42.98	2063.00
	Head injury	43	49.37	2123.00
	Total	91		
L1FRIEND	Normal controls	49	44.44	2177.50
	Head injury	44	49.85	2193.50
	Total	93		
L1SEX	Normal controls	49	49.00	2401.00
	Head injury	44	44.77	1970.00
	Total	93		
L1DAYS	Normal controls	49	44.72	2191.50
	Head injury	44	49.53	2179.50
	Total	93		
L1AIMS	Normal controls	48	48.33	2320.00
	Head injury	44	44.50	1958.00
	Total	92		
L1YRSELF	Normal controls	49	46.21	2264.50
	Head injury	44	47.88	2106.50
	Total	93		
L1RELIGI	Normal controls	48	46.68	2240.50
	Head injury	43	45.24	1945.50
	Total	91		

APPENDIX 7.4.

Mean ranks and numbers in both the brain injured and the control group on the Future Expectations Scale

Ranks

	Group	N	Mean Rank	Sum of Ranks
F1CARE	Normal controls	48	35.74	1715.50
	Head injury	45	59.01	2655.50
	Total	93		
F1INDEP	Normal controls	49	37.18	1822.00
	Head injury	45	58.73	2643.00
	Total	94		
F1PHYS	Normal controls	48	39.86	1913 50
	Head injury	42	51.94	2181.50
	Total	90		
F1MENTAL	Normal controls	48	38.39	1842.50
	Head injury	42	53.63	2252.50
	Total	90		
F1LEISUR	Normal controls	49	39.84	1952.00
	Head injury	45	55.84	2513.00
	Total	94		
F1WORK	Normal controls	49	36.76	1801.00
	Head injury	44	58.41	2570.00
	Total	93		
F1FINANC	Normal controls	48	46.67	2240.00
	Head injury	43	45.26	1946.00
	Total	91		
F1PARTNE	Normal controls	48	37.11	1781.50
	Head injury	44	56.74	2496.50
	Total	92		
F1FAMILY	Normal controls	49	44.99	2204.50
	Head injury	45	50.23	2260.50
	Total	94		
F1FRIEND	Normal controls	48	41.00	1968.00
	Head injury	44	52.50	2310.00
	Total	92		
F1SEX	Normal controls	48	38.90	1867.00
	Head injury	45	55.64	2504.00
	Total	93		
F1DAYS	Normal controls	48	41.39	1986.50
	Head injury	44	52.08	2291.50
	Total	92		
F1AIMS	Normal controls	49	39.09	1915.50
	Head injury	44	55.81	2455.50
	Total	93		
F1YRSELF	Normal controls	48	39.99	1919.50
	Head injury	45	54.48	2451.50
	Total	93		
F1RELIGI	Normal controls	48	49.18	2360.50
	Head injury	43	42.45	1825.50
	Total	91		
F1HAPPY	Normal controls	47	40.71	1913.50
	Head injury	44	51.65	2272.50
	Total	91		
F1HOPEFU	Normal controls	48	44.27	2125.00
	Head injury	45	49.91	2246.00
	Total	93		

APPENDIX 7.5.

Test Statistics for the Mann-Whitney Independent Samples Comparison between the Brain injured group and the control group on the Satisfaction with Life Domains Scale, the Life Priority Scale, and the Future Expectations Scale

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Test statistics for the Satisfaction with Life Domains Scale

Test Statistics[a]

	S1CARE	S1INDEP	S1PHYS	S1MENTAL	S1LEISUR	S1WORK	S1FINANC	S1PARTY	S1PARTN	S1FAMILY	S1FRIEND	S1SEX	S1DAYS	S1AIMS	S1YRSELF	S1RELIGI	S1LIFE
Mann-Whitney U	1063.000	806.000	932.000	639.500	808.500	1048.500	834.500	228.000	91.000	997.500	908.500	580.500	1034.000	1007.000	810.000	646.000	988.000
Wilcoxon W	2239.000	1887.000	2108.000	1815.500	1936.500	2224.500	2010.500	399.000	526.000	2222.500	2084.500	1615.500	2069.000	2135.000	1891.000	1507.000	2023.000
Z	-.877	-2.496	-1.658	-3.908	-2.586	-.606	-2.375	-.767	-3.466	-.819	-1.839	-3.798	-.368	-.758	-1.986	-1.193	-.730
Asymp. Sig. (2-tailed)	.380	.013	.097	.000	.010	.545	.018	.443	.001	.413	.066	.000	.713	.448	.047	.233	.465

a. Grouping Variable: Group

Test statistics for the Life Priority Scale

Test Statistics[a]

	L1CARE	L1INDEP	L1PHYS	L1MENTAL	L1LEISUR	L1WORK	L1FINANC	L1PARTY	L1PARTN	L1FAMILY	L1FRIEND	L1SEX	L1DAYS	L1AIMS	L1YRSELF	L1RELIGI
Mann-Whitney U	962.000	1048.500	896.500	1032.000	1082.000	994.000	892.000	225.000	185.500	887.000	952.500	980.000	966.500	968.000	1039.500	999.500
Wilcoxon W	2138.000	2273.500	2121.500	2022.000	2117.000	1984.000	2020.000	330.000	321.500	2063.000	2177.500	1970.000	2191.500	1958.000	2264.500	1945.500
Z	-1.012	-.472	-1.739	-.413	-.164	-.511	-1.044	-.380	-1.184	-1.224	-1.024	-.796	-.904	-.732	-.317	-.264
Asymp. Sig. (2-tailed)	.311	.637	.082	.679	.869	.609	.296	.704	.236	.221	.306	.426	.366	.464	.752	.792

a. Grouping Variable: Group

Test statistics for the Future Expectations Scale

Test Statistics[a]

	F1CARE	F1INDEP	F1PHYS	F1MENTAL	F1LEISUR	F1WORK	F1FINANC	F1PARTNE	F1FAMILY	F1FRIEND	F1SEX	F1DAYS	F1AIMS	F1YRSELF	F1RELIGI	F1HAPPY	F1HOPEFU	F1PASFUT
Mann-Whitney U	539.500	597.000	737.500	666.500	727.000	576.000	1000.000	605.500	979.500	792.000	691.000	810.500	690.500	743.500	879.500	785.500	949.000	1011.500
Wilcoxon W	1715.500	1822.000	1913.500	1842.500	1952.000	1801.000	1946.000	1781.500	2204.500	1968.000	1867.000	1986.500	1915.500	1919.500	1825.500	1913.500	2125.000	2139.500
Z	-4.542	-3.949	-2.256	-2.869	-2.940	-4.003	-.262	-3.639	-.958	-2.128	-3.092	-1.989	-3.087	-2.657	-1.235	-2.034	-1.029	-.367
Asymp. Sig. (2-tailed)	.000	.000	.024	.004	.003	.000	.794	.000	.338	.033	.002	.047	.002	.008	.217	.042	.304	.714

a. Grouping Variable: Group

APPENDIX 8.1.

Pearson correlations between all injury-related variables, adjustment-related variables, and subjective quality of life

Correlations

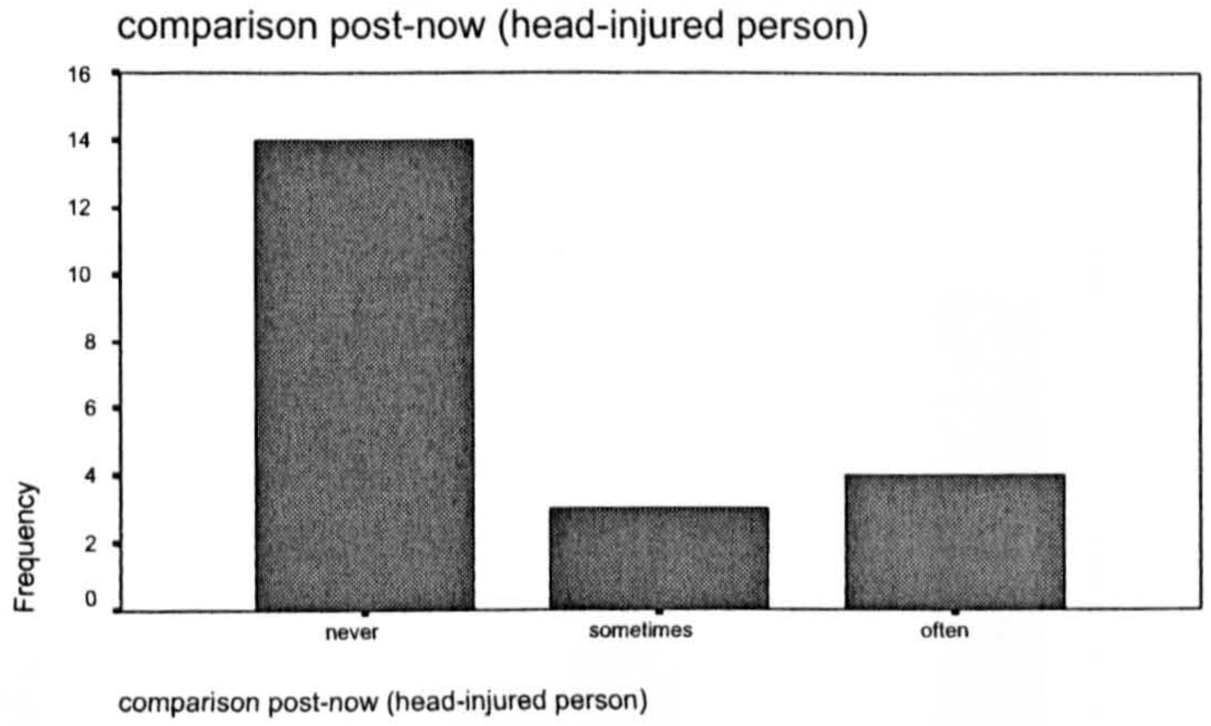
		Satisfaction with Life Scale	Post traumatic amnesia	Total Cognitive Deficits	Carer-perceived neurobehavioural problems	Patient-perceived neurobehavioural problems	Awareness of limitations	Acceptance of Limitations	Past - future Orientation
Satisfaction with Life Scale	Pearson Correlatio	1.000	.109	-.135	-.332*	-.554**	.152	.625**	.607**
	Sig. (1-tailed)	.	.249	.246	.021	.000	.192	.000	.000
	N	46	41	28	38	46	35	41	42
Post traumatic amnesia	Pearson Correlatio	.109	1.000	.486**	.351*	-.182	.343*	-.194	-.017
	Sig. (1-tailed)	.249	.	.005	.019	.125	.027	.122	.459
	N	41	42	27	35	42	32	38	39
Total Cognitive Deficits	Pearson Correlatio	-.135	.486**	1.000	.457*	.193	.313	-.481**	-.345*
	Sig. (1-tailed)	.246	.005	.	.011	.158	.073	.006	.034
	N	28	27	29	25	29	23	27	29
Carer-perceived neurobehavioural problems	Pearson Correlatio	-.332*	.351*	.457*	1.000	.537**	.542**	-.600**	-.197
	Sig. (1-tailed)	.021	.019	.011	.	.000	.000	.000	.118
	N	38	35	25	39	39	36	35	38
Patient-perceived neurobehavioural problems	Pearson Correlatio	-.554**	-.182	.193	.537**	1.000	-.385*	-.658**	-.495**
	Sig. (1-tailed)	.000	.125	.158	.000	.	.010	.000	.000
	N	46	42	29	39	48	36	43	44
Awareness of limitations	Pearson Correlatio	.152	.343*	.313	.542**	-.385*	1.000	.061	.293*
	Sig. (1-tailed)	.192	.027	.073	.000	.010	.	.370	.044
	N	35	32	23	36	36	36	32	35
Acceptance of Limitatio	Pearson Correlatio	.625**	-.194	-.481**	-.600**	-.658**	.061	1.000	.514**
	Sig. (1-tailed)	.000	.122	.006	.000	.000	.370	.	.000
	N	41	38	27	35	43	32	44	40
Past - future Orientation	Pearson Correlatio	.607**	-.017	-.345*	-.197	-.495**	.293*	.514**	1.000
	Sig. (1-tailed)	.000	.459	.034	.118	.000	.044	.000	.
	N	42	39	29	38	44	35	40	45

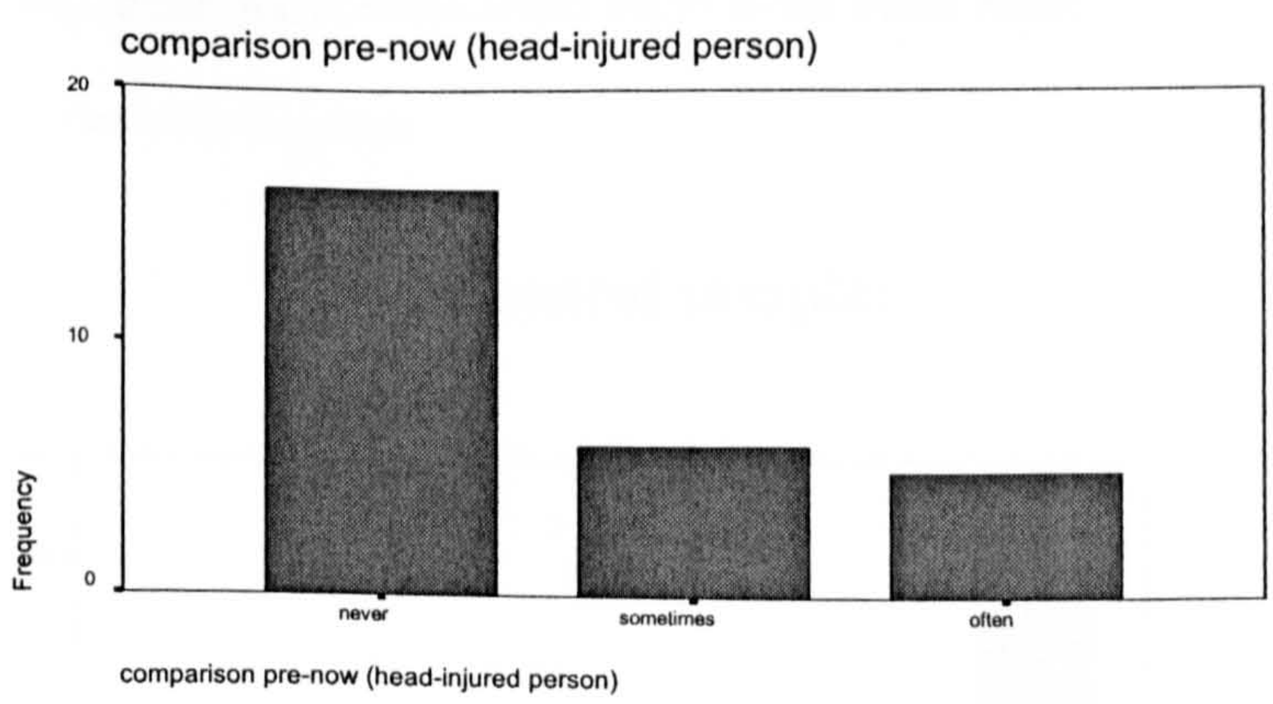
*. Correlation is significant at the 0.05 level (1-tailed).

**. Correlation is significant at the 0.01 level (1-tailed).

APPENDIX 9.1.

Distributions of 'pre-now comparison', and 'post-now comparison'.

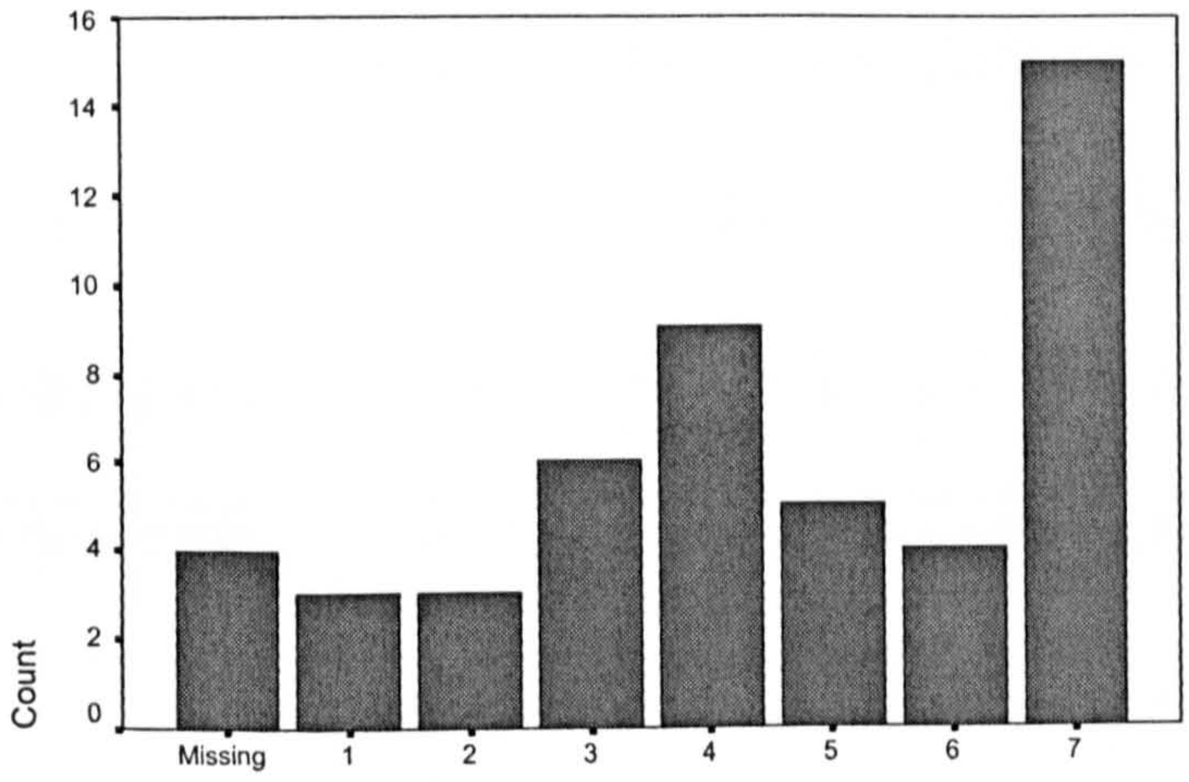




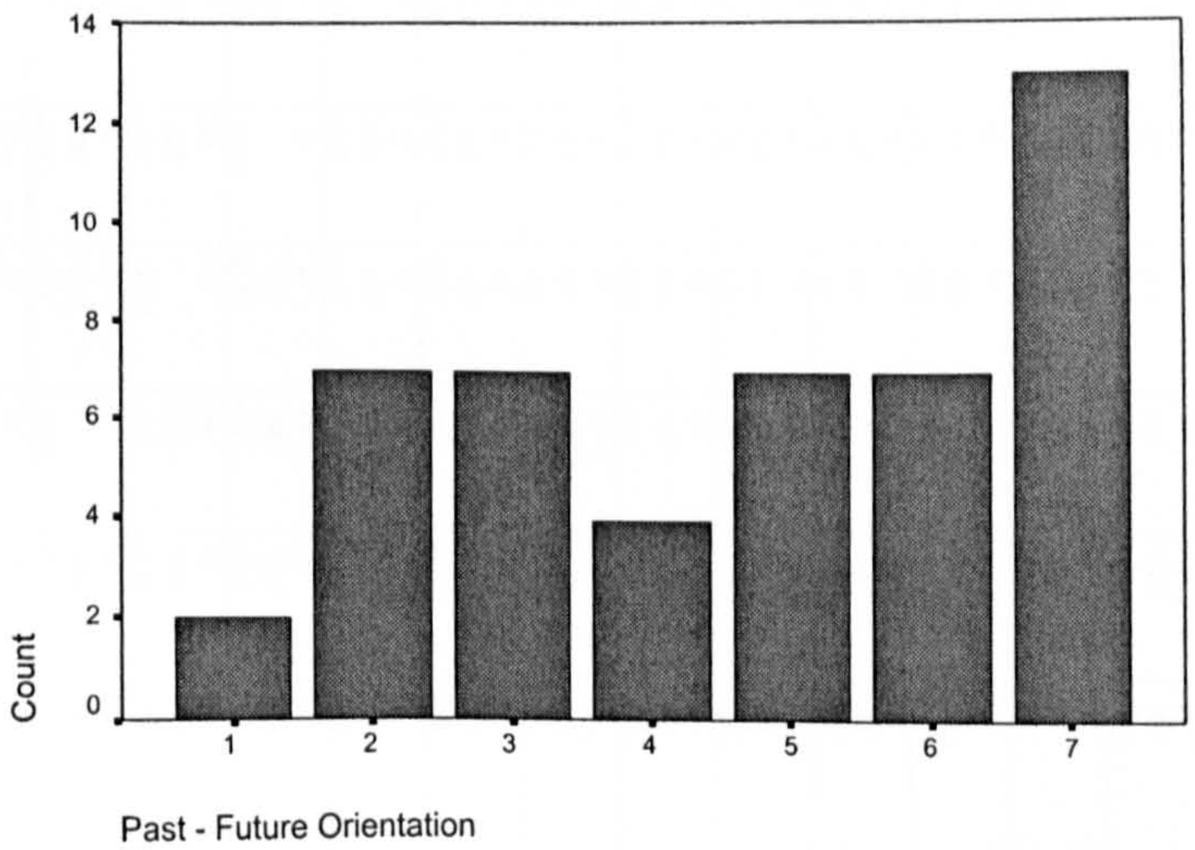
APPENDIX 9.2.

Distributions of 'past-future orientation' for the brain injured group and the control sample.

Brain injured people:



Control sample:



APPENDIX 11.1.

Correlation matrix of the Satisfaction with Life Scale and all domains of satisfaction in the brain injured group

Correlations

		Satisfaction with Life Scale	Ability to take care of oneself	Level of independence	Physical abilities	Mental abilities	Leisure activities	Work/Education	Financial position	Having a partner	Not having a partner	Family life	Friendships	Sexual life	The way days are spent	Aims and purposes in life	Satisfied with oneself	Religious life
Satisfaction with Life Scale	Pearson Correlation	1.000	.412**	.433**	.478**	.711**	.690**	.538**	.321*	.757**	.351*	.545**	.524**	.586**	.596**	.471**	.804**	.252
	Sig. (1-tailed)	.	.002	.002	.000	.000	.000	.000	.016	.000	.036	.000	.000	.000	.000	.001	.000	.072
	N	48	45	43	45	45	44	44	45	17	27	42	45	42	42	44	43	35
Ability to take care of oneself	Pearson Correlation	.412**	1.000	.466**	.374**	.515**	.313*	.436**	.145	.628**	-.301	.074	.313*	.191	.323*	.379**	.364**	.529**
	Sig. (1-tailed)	.002	.	.001	.004	.000	.018	.001	.163	.003	.056	.314	.015	.105	.015	.004	.008	.000
	N	45	48	46	48	48	47	47	48	18	29	45	48	45	45	47	46	37
Level of independence	Pearson Correlation	.433**	.466**	1.000	.533**	.482**	.471**	.540**	.296*	.473*	.117	.260*	.339*	.279*	.523**	.568**	.505**	.449**
	Sig. (1-tailed)	.002	.001	.	.000	.000	.001	.000	.023	.028	.277	.043	.011	.032	.000	.000	.000	.003
	N	43	46	46	46	46	45	45	46	17	28	45	46	45	44	45	45	36
Physical abilities	Pearson Correlation	.478**	.374**	.533**	1.000	.662**	.517**	.434**	.139	.514*	-.296	.264*	.259*	.274*	.343*	.433**	.487**	.480**
	Sig. (1-tailed)	.000	.004	.000	.	.000	.000	.001	.173	.015	.059	.040	.038	.034	.011	.001	.000	.001
	N	45	48	46	48	48	47	47	48	18	29	45	48	45	45	47	46	37
Mental abilities	Pearson Correlation	.711**	.515**	.482**	.662**	1.000	.619**	.625**	.269*	.611**	.153	.362**	.452**	.427**	.486**	.560**	.676**	.527**
	Sig. (1-tailed)	.000	.000	.000	.000	.	.000	.000	.032	.004	.214	.007	.001	.002	.000	.000	.000	.000
	N	45	48	46	48	48	47	47	48	18	29	45	48	45	45	47	46	37
Leisure activities	Pearson Correlation	.690**	.313*	.471**	.517**	.619**	1.000	.674**	.480**	.800**	.058	.475**	.695**	.600**	.719**	.675**	.748**	.165
	Sig. (1-tailed)	.000	.018	.001	.000	.000	.	.000	.000	.000	.383	.001	.000	.000	.000	.000	.000	.164
	N	44	47	45	47	47	47	47	47	17	29	44	47	44	45	46	45	37
Work/Education	Pearson Correlation	.538**	.436**	.540**	.434**	.625**	.674**	1.000	.282*	.593**	.209	.501**	.634**	.323*	.638**	.729**	.659**	.148
	Sig. (1-tailed)	.000	.001	.000	.001	.000	.000	.	.028	.006	.138	.000	.000	.016	.000	.000	.000	.192
	N	44	47	45	47	47	47	47	47	17	29	44	47	44	45	46	45	37
Financial position	Pearson Correlation	.321*	.145	.296*	.139	.269*	.480**	.282*	1.000	.678**	-.089	.236	.428**	.142	.495**	.155	.240	-.088
	Sig. (1-tailed)	.016	.163	.023	.173	.032	.000	.028	.	.001	.323	.059	.001	.175	.000	.149	.054	.303
	N	45	48	46	48	48	47	47	48	18	29	45	48	45	45	47	46	37
Having a partner	Pearson Correlation	.757**	.628**	.473*	.514*	.611**	.800**	.593**	.678**	1.000	.a	.545*	.657**	.895**	.827**	.664**	.862**	.434
	Sig. (1-tailed)	.000	.003	.028	.015	.004	.000	.006	.001	.	.	.012	.002	.000	.000	.001	.000	.091
	N	17	18	17	18	18	17	17	18	18	0	17	18	16	16	18	17	11
Not having a partner	Pearson Correlation	.351*	-.301	.117	-.296	.153	.058	.209	-.089	.a	1.000	.111	.325*	.412*	.255	.125	.394*	-.194
	Sig. (1-tailed)	.036	.056	.277	.059	.214	.383	.138	.323	.	.	.286	.043	.015	.095	.263	.019	.177
	N	27	29	28	29	29	29	29	29	0	29	28	29	28	28	28	28	25
Family life	Pearson Correlation	.545**	.074	.260*	.264*	.362**	.475**	.501**	.236	.545*	.111	1.000	.536**	.434**	.583**	.543**	.522**	.052
	Sig. (1-tailed)	.000	.314	.043	.040	.007	.001	.000	.059	.012	.286	.	.000	.002	.000	.000	.000	.384
	N	42	45	45	45	45	44	44	45	17	28	45	45	44	43	44	44	35
Friendships	Pearson Correlation	.524**	.313*	.339*	.259*	.452**	.695**	.634**	.428**	.657**	.325*	.536**	1.000	.527**	.728**	.637**	.691**	.077
	Sig. (1-tailed)	.000	.015	.011	.038	.001	.000	.000	.001	.002	.043	.000	.	.000	.000	.000	.000	.326
	N	45	48	46	48	48	47	47	48	18	29	45	48	45	45	47	46	37
Sexual life	Pearson Correlation	.586**	.191	.279*	.274*	.427**	.600**	.323*	.142	.895**	.412*	.434**	.527**	1.000	.535**	.497**	.712**	.149
	Sig. (1-tailed)	.000	.105	.032	.034	.002	.000	.016	.175	.000	.015	.002	.000	.	.000	.000	.000	.194
	N	42	45	45	45	45	44	44	45	16	28	44	45	45	43	44	44	36
The way days are spent	Pearson Correlation	.596**	.323*	.523**	.343*	.486**	.719**	.638**	.495**	.827**	.255	.583**	.728**	.535**	1.000	.682**	.696**	.061
	Sig (1-tailed)	.000	.015	.000	.011	.000	.000	.000	.000	.000	.095	.000	.000	.000	.	.000	.000	.360
	N	42	45	44	45	45	45	45	45	16	28	43	45	43	45	45	45	37
Aims and purposes in life	Pearson Correlation	.471**	.379**	.568**	.433**	.560**	.675**	.729**	.155	.664**	.125	.543**	.637**	.497**	.682**	1 000	.615**	.243
	Sig. (1-tailed)	.001	.004	.000	.001	.000	.000	.000	.149	.001	.263	.000	.000	.000	.000	.	.000	.073
	N	44	47	45	47	47	46	46	47	18	28	44	47	44	45	47	46	37
Satisfied with oneself	Pearson Correlation	.804**	.364**	.505**	.487**	.676**	.748**	.659**	.240	.862**	.394*	.522**	.691**	.712**	.696**	.615**	1.000	.302*
	Sig. (1-tailed)	.000	.006	.000	.000	.000	.000	.000	.054	.000	.019	.000	.000	.000	.000	.000	.	.035
	N	43	46	45	46	46	45	45	46	17	28	44	46	44	45	46	46	37
Religious life	Pearson Correlation	.252	.529**	.449**	.480**	.527**	.165	.148	-.088	.434	-.194	.052	.077	.149	.061	.243	.302*	1.000
	Sig. (1-tailed)	.072	.000	.003	.001	.000	.164	.192	.303	.091	.177	.384	.326	.194	.360	.073	.035	.
	N	35	37	36	37	37	37	37	37	11	25	35	37	36	37	37	37	37

**. Correlation is significant at the 0.01 level (1-tailed).

*. Correlation is significant at the 0.05 level (1-tailed).

a. Cannot be computed because at least one of the variables is constant.